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ABSTRACT

The monograph contains seven papers on developing and maintaining cooperation between parents of handicapped children and education professionals. B. Pattison reviews the history of parent involvement and advocacy and offers suggestions for improving school and community relations in "The Early Years and Now: The History of the Parent Advocacy Movement." In "Parents and Professionals," D. Lipton describes her experiences as the mother of a child with cerebral palsy. M. Peters and M. Noel ("Parent Perspectives about Professional and Parent Cooperation") present the reflections of 12 parents of handicapped children gathered from structured interviews. "The Advocacy Process" by W. Dussault, stresses the need to explore, negotiate, and compromise before initiating due process. Three papers then describe educators' attempts to improve the parent-professional communication process: "An Integrative Model of Parent Involvement" (J. Wright); "Maximizing Evaluation of Handicapped Children by Integrating the Efforts of Parents, Child, and School" (A. Greenwood); and "Parent Involvement: A Challenge for Teacher Training Institutions" (R. Kroth, H. Otteni, and P. Parks). (CL)

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Program Development
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University of Washington

Building an Alliance for Children:

Parents and Professionals

Edited by
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Series Editor

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Preface

Special Education Programs (SEP) (formerly Office of Special Education) provides technical assistance and other support services to a national network of federally funded Handicapped Children's Model Programs (HCMP) and Special Needs Projects (SNP). These projects aim toward achieving a high quality of services to children (with handicapping conditions) and their families by providing innovative, well-managed, and demonstrably effective programs. Cooperation between parents and professionals has been a prominent goal of these projects. A basic assumption underlying the desire for strong parent-professional cooperation is that a solid basis of communication will enhance the quality of the educational programs planned for handicapped children. But it is also a reality that many barriers exist which make it difficult for parents and professionals to form an alliance that will

always put the best interests of the child first. This monograph addresses strategies for improving the opportunities whereby parents and professionals can cooperatively plan and implement educational programs for handicapped children.

Two years ago a group of concerned parents of handicapped children were invited by SEP to share their parenting experiences with professionals. The major purpose of this meeting was to establish effective and sensitive ways for parents and professionals to communicate and cooperate in the educational planning for handicapped children. The parents attending this meeting were encouraged to present their frank answers to such questions as: What kind of obstacles do you face in finding an appropriate educational program for your child? What do you do to break down the barriers? What effective means are there by which parents and professionals can cooperate in order to help provide appropriate educational programs for handicapped children.

The meeting provided a forum for parents and professionals to examine their own experiences, contrast any conflict of interests that arise when parents and professionals interact, and become more sensitive to the needs of one another. The parents described their experiences, offered criticisms and occasional praise, pointed out pitfalls to avoid, and made suggestions for future action. The professionals listened, asked questions, tried to explain why particular decisions may have been made by professionals in the past, and offered solutions to problems. Thus, the meeting provided a setting wherein parents and professionals could examine similar problems from two perspectives. The parents reported that contrary to past experiences with professionals, they felt their opinions and experiences were "accepted, valued, and would be taken seriously" by the professionals present at the meeting. The professionals reported that they were

able to receive the information from the parents in a more objective manner. As one professional put it, "I think this is the first time I have really heard a parent talking." At the close of the meeting, several members expressed a desire to make this information available to other parents and professionals. It was decided to produce a monograph devoted to improving communication and cooperation between parents and professionals--toward developing an alliance for children.

A general theme of this monograph is that cooperation among any group of people requires a certain amount of interpersonal communication. Information is not simply offered and received. The communication process will more likely result in positive outcomes if one allows the participants to adjust their understandings and attitudes, to make them congruent, or to determine how and where one member agrees or disagrees with another. Thus, communication between persons is enhanced when a commonality exists, such as a common aim, problem, or interest. In this case, the common interest is the handicapped child. The following articles share the same concern--how parents and professionals can improve their communication skills and ultimately develop a cooperative mode of interaction.

The chapters in this monograph examine various aspects related to developing and maintaining a cooperative atmosphere between parents of handicapped children and the professionals providing educational programs to these children. Each author looks at the problem from a different perspective.

In the first chapter, "Parent Involvement in Special Education: The Early Years and Now," Barbara Pattison presents the recent trends of parent involvement and advocacy, especially as they relate to the education of handicapped children. She also reviews special education programs, discusses the

development of Public Law 94-142, and suggests ways in which educators and parents may facilitate a partnership between home, school, and community. Pattison clearly outlines the dramatic changes in public policy for persons with handicapping conditions and points out the inevitable problems that develop whenever change is initiated. By drawing upon her extensive experience as an advocate for special education programs within the public school system and as a liaison person between parents and professionals, she is able to offer practical suggestions for improving school and community relations.

Diane Lipton's paper, "Parents and Professionals," is an elegant and poignant personal account of a mother coming to terms with having a handicapped child, and the ensuing struggles with professionals in her attempts to provide her daughter with an appropriate educational program. By describing her feelings and experiences, she offers practical ideas of how to break down the tensions and conflicts between parents and professionals. The author points out that this is crucial now when all that has been achieved by and for persons with handicapping conditions is being threatened by the political process.

Diane Lipton was the recipient of the Distinguished Parent Award from The Association for the Severely Handicapped in November 1981.

"Dealing With the System: Twelve Perspectives" by Marie-Gaasholt and Margaret Noel offers additional evidence of the unique strengths demonstrated by parents of handicapped children. The chapter presents the reflections of twelve parents involved with obtaining appropriate educational situations for their handicapped children. The major focus is upon the parents' experiences when interacting with various professionals (e.g., educators, psychologists, medical doctors, physical therapists).

The aim of the chapter is to describe the present status of parent-professional communication and cooperation, as described by these parents, and to present some practical suggestions that might improve future interactions.

The next paper, "The Advocacy Process," is written by William Dussault, drafter of many laws establishing rights of handicapped people to an education. His chapter offers a pragmatic look at how parents and professionals can become advocates for children with handicapping conditions. Although the author points out that the term advocacy has often become synonymous with the term "adversary," he does not encourage an advocate to take an adversary position. Rather, the well-prepared advocate should explore the avenues of compromise and negotiation whenever there is a reasonable chance to believe that the child's program needs can be met. The future advocate is offered a set of guidelines based upon the author's experience in more than 100 special education problem situations over the past five years. The author's final comment is that a good advocate should avoid due process except as a last possible resort. But once that becomes necessary, the advocate must be prepared to fight and win at all costs.

Judith Sewell Wright's paper, "An Integrative Model of Parent Involvement," is the first of three chapters focusing upon recent attempts by educators to improve the parent-professional communication process. This chapter is devoted to parent involvement activities during the early years of a child's life. Three main modes of parental involvement in their handicapped child's education are reviewed; 1) training to train their children, 2) parental counseling, and 3) facilitating parent-child interactions. From this review the author draws the conclusions that each mode in itself is not sufficient to maximize the child's developmental progress. The author continues by describing a model of parent involvement which was developed at the

Early Childhood Intervention Program at the University of Illinois. The model synthesizes all three modes, resulting in a holistic model in which each component interacts with and compliments the other. The author's philosophy is that educators cannot teach parents everything they need to know throughout their child's lifetime, but educators can set the stage for future growth. Providing parental training along with parental counseling and facilitation of parent-child interaction, provides this forum.

Ms. Wright is the Director of the Early Childhood Intervention Program at the University of Illinois.

In "Maximizing Evaluation of Handicapped Children by Integrating the Efforts of Parent, Child, and School," Albert Greenwood emphasizes that the working relationship between parents, child, and school must take on a team spirit. It is necessary to have each team member's contributions to ensure the quality and equality of the many activities undertaken during a child's special education experience. The author's experience as Director of a Model Program for the Diagnosis and Education of Neurologically Impaired Children at Good Samaritan Hospital in Portland, Oregon has led him to develop a "Useful Participation Model" for establishing equally shared effort and thus responsibility between parents, school, and the child. The chapter provides the reader with a framework for developing cooperative participation, especially during the early phases of intervention. Fourteen steps have been identified as prerequisites to productive effort between families and schools. It is the author's opinion that participation, as defined in his chapter, cannot emerge without an attempt to work through each step. Furthermore, the process of working through these steps will clarify the direction that the participation may take. The author encourages readers to look at the special education process in a more qualitative, interactive,

and personalized manner. It should be considered an ongoing process with a high degree of interdependence between each phase in the special education process.

The final chapter, "Parent Involvement: A Challenge for Teacher Training Institutions," by Roger Kroth, Harriet Otteni, and Paula Parks from the Parent Involvement Center in Albuquerque, New Mexico presents a comprehensive model of parent involvement and subsequent implications for teacher training programs. The Mirror Model of Parental Involvement is an attempt to respect the strengths that parents have, as well as to acknowledge their needs. The authors agree that not all parents will have the strength, knowledge, time, or energy to take advantage of all the "help" that professionals have to offer, but all parents have information about the child that can benefit the educational program. The authors present four implications for teacher training that can be drawn from the assumptions underlying the Mirror Model. These implications involve teacher sensitivity, direction of parent training, communication skills, and acquisition of skills relevant to parent-teacher interaction. Specific teacher skills are described and strategies for training are presented. The authors take the position that parent-teacher interactions should be integral parts of any teaching training program. As no other group of people has the frequent and sustained contact with parents that teachers do, nor is any other group so vested with the trust and hope for the success of their children, it seems only reasonable that teachers be taught the competencies that will improve the relationship between school and home.

The contributions in this monograph are provocative and insightful commentaries about the complex issues connected with parent and professional cooperation. The authors, whether they write from the viewpoint of a parent, attorney, educator, or psychologist,

support the theme that parents and professionals must build an alliance that will enhance the ultimate developmental potential of handicapped children. Consciously or unconsciously, parents and professionals are sculptors, helping to shape the child's destiny. We must therefore, work together, communicating openly and honestly while taking risks of personal investment. We must keep learning how to listen to each other in an accurate, sensitive, and nondefensive manner. We must use the strengths of one another because the fact is, we are all in the same battle together--the ongoing struggle to do the best we can for our children under difficult circumstances.

A very sincere thank you is extended to all the parents who contributed to this monograph, either directly or indirectly. The message to the parents reading these chapters is very simple: Trust yourself. Because of your love, concern, and knowledge for your child, you can do things for your children which no one else can do. The message to the professionals is also simple, listen to the parents and offer information in a careful and thoughtful manner. If we can follow the advice given throughout this monograph, we can establish an alliance for children.

M.P.

Building An Alliance for Children

The Early Years and Now: The History of the Parent Advocacy Movement

Barbara J. Pattison

Through the years educators have viewed parent involvement in the educational process of their children with varying degrees of enthusiasm. There have been periods when parents were the natural advocates of their children, and partners in the educational process. At other times the economic conditions and prevailing social thought regarding child rearing practices and theories of child development discouraged a close alliance between parents and educators. A brief look at the recent trends of parent involvement may help place the present concern for parent involvement and advocacy in perspective and provide guidelines for meaningful cooperation between the home and the school, especially as these trends relate to the education of children with handicapping conditions.

In the 1950s James Hymes (1974), an advocate of close home-school relations, persuaded teachers and parents to come together for the benefit of their children, but his pleas were not readily followed. He describes the educators' reaction to his proposition by writing: "...few (teachers) felt any driving pressure to push toward closer, warmer, more continuous, more effective relationships" (p. 1). A laissez-faire attitude toward parent involvement was typical of educators until the late 1960s and 1970s, when parent involvement in the educational process of their children took a new direction. The increased concern for parent involvement was in part due to political pressure. John F. Kennedy and Lyndon B. Johnson were both strong supporters of federal programs, and the general policy of a majority of the federal programs, such as Head Start and the Elementary and Secondary School Acts, was to increase cooperation between home, school, and community. With the establishment of Follow Through and Right-to-Read programs, parent involvement was not only encouraged, it was required. Parents were expected to participate in policy decisions. Those educators working under the regulations of the federal programs could no longer decide if parents should be included in the educational planning of a program for their child. Parents and educators were expected to work together. These expectations had an indirect influence on the parents of children with handicapping conditions. As other parents became more visible and were permitted to let their opinions be incorporated into policy statements regarding the educational program for their children, the parents of children with handicapping conditions began to realize that they and their children had rights within the school system. As their awareness was raised, they began to express their desires and concerns to elected officials. In 1975 Public Law 94-142 (The Education for All Handicapped Children Act) was established. This law is the culmination of laws and litigation directed

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toward the delivery of equal educational opportunities for all children with handicapping conditions. PL 94-142, more than any laws that have preceded it, gives parents the right and responsibility to be involved actively in the planning and implementation of their children's education.

There are many reasons why PL 94-142 was necessary. A full account of the struggle to obtain equal rights for the handicapped would take one through the past from the time when handicapped persons were outcast, then feared, and finally accepted...or at least accepted by a few. Usually those accepting persons were the parents of children with handicapping conditions. As Berger (1981) said in her excellent overview of parent involvement in the public schools: "Parents were the driving force in seeing that legislation was passed. Parents again will be the force that will see that the intent of the law is achieved and maintained" (p. 278).

The remainder of this paper will provide a brief review of special education programs, followed by a discussion of the development of PL 94-142, and finally will present suggestions for educators and parents which may facilitate a partnership between home, school, and community.

Development of Special Education Programs

Isolationism

Special education programs, according to Weintraub (1971), can be traced back to the first state schools and institutions for the handicapped. The United States was not particularly innovative in the development of special education programs; American

educators adopted the European segregated concept of residential schools and asylums. Most of these early programs ignored the needs of the severely or multiply handicapped and involved only the blind, deaf, or mildly mentally retarded populations.

The isolationist philosophy for the handicapped was demonstrated when Thomas Gallaudet established the first American residential school for the deaf in Hartford, Connecticut in 1817. This school, now known as the American School for the Deaf, became the first venture of the federal government into handicapped education when the school was given a federal endowment the following year. Twelve years later, in 1829, the Massachusetts School for the Blind was established. It was followed by the creation of the New York Institution for the Blind in 1832. Several other states followed suit and began operating separate schools for the blind.

The Massachusetts School for the Feeble-minded was established in 1848. By establishing a separate facility for the retarded, this school accepted the prevailing attitude that the retarded population should be isolated from the mainstream of society. Pennsylvania followed suit and opened a separate school for the retarded in 1852, followed by separate schools in Ohio, Connecticut, and Illinois. Support was provided to these schools by state allocations.

The majority of severely impaired children were not eligible for admission to any school. Parents were expected to provide full-time care for their children. It was a common sight in the midwest to see small houses, separated from the family, which were used as residences for severely or multiply handicapped individuals. Handicapped individuals were isolated from society even at home.

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Together--Yet Alone

Special classes for children with handicapping conditions began to appear on a limited basis in the public school system toward the end of the 19th century. New Jersey legislators took a positive stance in 1911 by requiring local school districts to serve certain types of children with handicapping conditions. Minnesota and New York passed similar legislation and agreed to provide funds for special classes in the regular school system. A survey conducted by the Bureau of Education in 1920 discovered the existence of 133 public school programs across the nation which were serving a limited number of mentally retarded citizens. The children were separated from their peers, but they were at least within the system.

Although there was some progress in developing special education programs for individuals with handicapping conditions, it is generally accepted that during the latter part of the nineteenth century a steady decline occurred in programs for the handicapped. Numerous reasons are given for the change. Hallahan and Kauffman (1978) list the following factors that may have affected the growth of special education: overzealous claims of effect; disagreement among professionals; lack of financial support; social, political, and economic turmoil following the Civil War; Darwin's theory of evolution; industrialization and urbanization; and the increase of immigrants who needed to be assimilated into the mainstream of American society.

The next major growth periods of special education occurred after World Wars I and II. The Soldiers Rehabilitation Act of 1918 provided vocational rehabilitation services to veterans who had become disabled in World War I. Nonmilitary disabled citizens were not offered the same services. After World War II, however, expanded services and

opportunities for the disabled community were made available to a wider spectrum of recipients.

In 1957 the Russians inadvertently made a positive impact on education in the United States by launching Sputnik. In true competitive spirit, the United States began to think in terms of providing the best education possible to the youth of the country. Although the National Defense Education Act of 1958 was not designed to provide direct service to exceptional and gifted students, it did open a back door to such programs. Other legislation in 1958 encouraged the expansion of teaching in the education of the mentally retarded through grants to institutions of higher learning and to state educational agencies. This legislation served as a catalyst for a nationwide training program for teachers of the handicapped.

President Kennedy's New Frontier Programs and President Johnson's War on Poverty provided a nurturing setting for special education programs. Gradually public support in the form of legislation and money for special education programs was introduced across the United States. Much of the legislation was of a permissive nature, meaning that the schools "may" provide special education. This trend would change with the passage of Public Law 94-142. PL 94-142 mandates that every school system in the nation "must" make provision for a free, appropriate public education for every child, from the ages of 3 to 21 regardless of type or degree of handicapping condition. Obviously a new era for special education programs in the United States had begun.

Background of Public Law 94-142

Public Law 94-142 is woven out of developments in three parallel areas: educational rights,

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residential rights, and civil rights. Dramatic changes have occurred in each area. As the previous review demonstrates, until the 1970s, children with handicapping conditions were accorded few basic rights. Most were commonly excluded from public schools on the grounds that they could not benefit from education. The United States constitution does not state that the right to an education is a fundamental right. The 5th and 14th Amendments do, however, guarantee equal protection under the law and ensure equal treatment for all persons under like circumstances and conditions, both in privileges conferred and liabilities imposed. These amendments support the argument for the constitutional right of education to every child. Federal courts have ruled in favor of a right to an appropriate education and have relied upon the "Due Process" and "equal provisions" of the United States Constitution as support of their conclusions. Even though this was the case, many children with handicapping conditions have been denied both Due Process and equal provisions in the past.

State laws that allowed children with handicapping conditions to be excluded in the past began to be challenged in Federal Courts. Positive judicial decisions, however, resulted in children with handicapping conditions receiving educational programs. Two landmark cases will be mentioned here.

The Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania, otherwise known as the PARC case [334 F. (Supp. 1257) E.D. PA 1971], determined that the state owed retarded children an appropriate program of education and training. Expert testimony in this action indicated that all mentally retarded persons are capable of achieving self-sufficiency and the remaining few, with education and training, are capable of achieving some degree of self-care. After several court hearings it was agreed not only to guarantee a free

public education to every child in Pennsylvania, but to guarantee that the child and his or her family would be given notice and the right of Due Process before school authorities made any change in the child's educational status. The PARC case has served as a model for similar cases in which parents of severely and profoundly retarded children have challenged the school's assertion that their children should be excluded from school on the grounds that they cannot profit from attending school programs (Abeson, 1976).

Another example of successful litigation to produce change concerning the rights of handicapped children is *Mills v. Board of Education of the District of Columbia* (348 F. Supp. 866 D.D.C. 1972). This suit was filed to compel the school board to provide appropriate education for retarded, physically handicapped, emotionally disturbed, hyperactive, and all other handicapped children. The plaintiffs charged that the district had failed to provide sufficient funds for children needing special services. The suit sought to establish the constitutional right of all children to an appropriate education. According to Abeson (1976),

It was charged that although these children could profit from an education... they were denied admission to the public schools or excluded after admission, with no provision for alternative educational opportunities or periodic review. Second, these children were excluded, suspended, reassigned, expelled, and transferred from regular public school classes without affording them procedural safeguards and due process of the law. (p. 241)

The final decision indicated that all children should be provided an appropriate education and that the school system must create Due Process procedures. The successful conclusions in both the

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Parc and Mills cases were influential in bringing about 36 "right to education" court decisions in 27 states.

This brief account points out that PL 94-142 is the most recent bill in a long series of federal actions that have determined the educational opportunities available to handicapped persons. Since 1827, when Public Law 91-8 was passed, there have been a total of 195 federal laws passed which have influenced the direction of special education programs in the United States. The federal government has made a significant commitment to the handicapped in the areas of health, education, welfare, housing, transportation, volunteer programs, training, and nutrition (LaVor, 1976).

PL 94-142--A Turning Point

PL 94-142, the "Education for All Handicapped Children Act," became law in 1975. The act established a stringent set of rules and regulations to assure that once-forgotten children are identified and served in the public school system. The federal government was directly involved with funding educational programs at all levels by the provision of money to local education agencies via the state education agency. However, many PL 94-142 mandates did not set well with local school district administrators. They felt that local control was their option and that they should be able to decide how the money would be spent, particularly when it came to special needs children. A major issue was "local control," or "who calls the shots," when it came to educating children.

PL 94-142 made dramatic changes in the way school districts deal with children and their parents. The act stipulates that a school district must:

1. Establish a Child-Find Program to locate all children needing special education services.
2. Provide the availability of full educational services to all children with a handicapping condition aged 3 to 21 by September 1, 1980.
3. Guarantee the right of all handicapped children to a free, appropriate public education at no cost to parents/guardians.
4. Provide on-going parent/guardian participation in decisions relating to their children.
5. Designate a surrogate to act for any child when parents/guardians are either unknown or unavailable or when the child is a legal ward of the state.
6. Guarantee complete Due Process procedures to protect the child's legal rights when the child is identified, placed, or not placed in a special education program.
7. Guarantee unbiased testing and assessment which recognize the child's native language and social-cultural background.
8. Protect the confidentiality of data and information.
9. Provide inservice training for school personnel and parents/guardians.
10. Provide all children with handicapping conditions an education to the maximum extent appropriate with children who are not handicapped, in the least restrictive environment based on the student's needs.

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11. Provide for a written Individual Education Program (IEP) for all children with a handicapping condition to be developed jointly with parents/guardians of each child and reviewed at least annually and revised if necessary.

These 11 points plunged parents into school system participation. School district personnel were required to work with parents and use parental expertise regarding their children.

Parents and The System

In the past parents of children with handicapping conditions were forced to join together for emotional and political support. Parents need a strong support base just to deal with the difficulties of parenting. They also need confidence to meet the problems they may encounter in getting their child into a school and in finding an appropriate program.

Much has been written about parents and their new involvement in the educational system; however, there appears to be a continuing reluctance on the part of both schools and parents to work as a team instead of hiding behind the traditional adversarial role of the "them vs. us" syndrome. One reason this adversarial position exists is that most parents and teachers wait too long before approaching each other. All too often a crisis has already arisen, and the child is in trouble. This is particularly true of children with handicapping conditions in which the handicap causes the child to react in ways not readily accepted by the school administration or staff. The waiting game usually produces frustration and guilt on both sides.

PL 94-142 emphasizes the development of a cooperative relationship between the parents and educators. It has also given added powers to the parents. The act is not intended to be a "gotcha," but rather a systematic way to set up guidelines and procedures to ensure that the most appropriate program for the child is developed. The watchword for both parents and educators must be "open-mindedness."

The IEP--Maximum Parent Involvement

The legislative history of PL 94-142 indicates that Congress intended the IEP to serve as an educational plan and to provide an opportunity for joint input by all individuals concerned with the child's education. The general definitional statement of the IEP which emerged from the Joint Explanatory Statement of Committee of Conference is: "A written statement, instructional objectives and specific educational services to be provided for each handicapped child is jointly developed by the local educational agency, the teacher, the parents and the child whenever appropriate" (United States Code of Congress and Administrative News, 1480, 1492, 1975).

Legislative intent as to the function of the IEP indicates three essential purposes. The first and most obvious is that it is to benefit the child. Congress overwhelmingly recognized the importance of individual attention to each child in order to assure that the needs of the handicapped child are adequately met. Senator Jennings Randolph of West Virginia stated:

It has been long recognized by educators that individualized attention to a child brings high reward to that child. Not every handicapped child is the same and by designing an educational program which addresses specific

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needs and problems, I believe that handicapped children will benefit more from our educational programs. (p. 120)

Another essential purpose of the IEP is to develop an educational plan to meet special needs. When developing the IEP, attention should be directed to the handicapped child and the group of children with whom he or she will interact in the integrated setting. Senator Randolph, in defining the objectives of the IEP, stated: "The IEP is a way of targeting the resources of our school system on handicapped children." The developmental process of any child is a 24-hour-a-day process and it is important that parents continue what is begun in school. The parents of handicapped children may be unaware of their children's special needs and may require information in order to contribute toward their development at home. "By involving the parents in the development of such plans, the benefits begun at school hopefully will be continued at home" (p. 121). The parents' participation in the development of the IEP is essential. If the process denies parents' familiarity with the child's needs, it essentially denies the child benefits as well.

Finally, the IEP is intended to benefit and serve the teacher. Because each handicapped child is unique, teachers, despite their experience in special education, need additional insight into the needs of each child. Furthermore, teachers with less experience fear the unknown when a handicapped child is introduced into the classroom. By participating in the IEP development meetings, parents, teachers, and children can negotiate a reasonable line of action.

Access to Files

All records, files, documents, and other materials which contain information directly relating to the student which are maintained by an educational agency, elementary school, office, or school district or university should be accessible to the parents. The type or location of the record does not matter. Discipline folders, psychological reports, health files, and other materials are to be provided upon parental request. Schools are required to provide parents with a list of all records maintained on the student. After a parent has requested the files, the school must grant the request immediately. If the records are destroyed after the request is made, it is a violation of the law. Schools may, however, remove or destroy records prior to the request.

Parents have the right to examine the records personally. If a school official agrees only to read from the records, the law is being violated. If parents don't understand the records, they should ask for an explanation. If the school personnel can't answer the questions, they must find someone who can. Parents can receive copies of the requested records at a reasonable cost, and they can amend the child's records if they feel the records are inaccurate, misleading, or in violation of the right of privacy.

Parents can request a Due Process hearing if the district refuses to make the requested amendment. The parents can insert a statement in the child's record even if the Due Process hearing upholds the district's decision. Parents will be informed before personally identifiable information can be destroyed. Wise parents will find out what the district's policies are regarding storage, retention, or destruction of school records, and who, besides themselves, can inspect the records.

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A Two-Way Street Allows Cooperation

Depending upon state laws, parents are legally responsible for their children during the first 18 to 21 years of their lives, and rightfully should have a voice in determining their educational programs. Professionals must provide parents with enough information to make appropriate decisions. Parents and professionals must work together to determine the best educational programs for each child. When mutual goals have been set, it is up to the professionals to select the methods and approaches for achieving the goals. Professionals must use their skills to assist parents in making appropriate decisions for their child. It is essential for young people with physical, mental, and emotional disabilities to learn the living skills they will need in order to function as independent adults. They must learn specific skills to enter the world of work. Lack of adequate school training adds to other barriers put up by society. Unfortunately, society still gears people to believe that obtaining a college education is the utmost level of achievement. This tends to present a problem if the student is not interested in college, and college is probably the last place a failing student wants to be placed. Parents and professionals must recognize that every day hundreds of students are being forced out of schools to become the so-called failures of the real world. These children have trouble with their identities in school and probably will have trouble identifying with another system. Children with handicapping conditions must fill out an application blank, go to an interview, and once they get a job, get to work on time. They can learn these skills at school. Parents, teachers, and students must realistically plan for the future and adjust their educational programs to reflect these demands.

In order to facilitate communication, professionals and parents must be informed of student rights and procedures. They must understand PL 94-142 and Section 504 of the Vocational Rehabilitation Act of 1973. They should recognize that PL 94-142 is an Educational Law and that Section 504 (PL 93-112) is a Civil Rights Law. The Right of Privacy Act protects parent's rights of confidentiality and access to school records. They must know that federal legislation has rules and regulations which mandate how the laws will be implemented and that each state has rules and regulations for implementing state law.

① Laws have impact on our daily lives and only by having a working knowledge of the legal process can parents, school, and child profit. Remember, the system can work to the benefit of the child, but everyone must be willing to work within the system. Parents, teachers, and other professionals are effective forces in influencing the life of the special needs child. It is important that each be able and willing to work together for the benefit of the child. Education, like life, is a two-way street.

The Right of Due Process

The right to Due Process of law, as provided by the 14th Amendment of the United States Constitution, refers to the right to have laws applied with enough safeguards that the individual will not be subject to arbitrary and unreasonable actions (Abeson, 1976). If parents object to the proposed initiation or changes in identification, assessment, or provision of special education or related services, they have the right to a Due Process hearing, presided over by an impartial hearing officer. The hearing officer is not an employee of the district. At the hearing, parents are allowed the right of

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counsel or the option of being accompanied by another individual informed on special education matters. The right to confront and cross-examine witnesses, the right to request the attendance of witnesses, the right to obtain a record of the hearing, the right to a written decision and finding of fact are all parts of the Due Process hearing.

Due Process hearings are intended to provide an opportunity for both parents and school to present their views concerning the educational status of the child before an unbiased individual--the hearing officer. The hearing officer is responsible for reaching a fair and impartial decision about the child's educational status based on the facts of the case and the best interest of the child.

Due Process hearings may be requested at any time after a child has been identified or not identified as having a handicapping condition. Hearings may be requested by parents, school district, or other persons who have primary responsibility for the child. Hearings may be requested when any issue arises regarding the assessment or educational placement of a child or when the provision of a free appropriate public education cannot be resolved.

The finding of fact is to be accomplished 45 days, and no longer, after the hearing has been requested in writing. However, when parents and professionals work together to serve the child, mediation should come before Due Process.

Parent and Professional--A Successful Endeavor

Effective collaboration between parents and professionals will be more likely when the professionals understand the parents' experiences with the child. Being a parent is probably one of life's most challenging tasks and is often one for

which there is little preparation. All parents struggle to master the job of child rearing. The ever-changing demands placed on parents as their children grow can be overwhelming. The major key to parents' meeting these demands is having a sense of confidence in their own abilities. Usually this self-confidence is closely linked to the successes their child has in mastering the challenges of everyday life. If the child succeeds, so do the parents. Difficulties in parenting are more likely to arise if the child has a disability. The disappointment and sense of "loss" in having a handicapped child, combined with the parents' lack of preparation can have traumatic repercussions. As a result, the entire family relationship can be affected.

When parents start to interact with professionals on behalf of their children, they may have had a lot of bad experiences, "put-downs," or feelings of inadequacy from previous educational encounters. Parents have reported that professionals show little visible concern for them. These negative experiences may be reinforced if professionals emphasize the areas about which the parents feel most unsuccessful and at the same time ignore the parents' strengths and skills. This "put-down" relationship breeds insecurity on the part of parents and often results in little, if any, cooperation. The parents feel their contribution is worthless--so why continue?

Most adults develop feelings of self-esteem and adequacy from experiences other than parenting. However, sometimes the difficulties their children have had can affect their own well-being and interfere in other aspects of their lives. The professional must be aware of these feelings and interact with the parents in ways that will increase self-confidence. Merely allowing the parents to do "busy work" or to fulfill the tasks of a home

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intervention program planned solely by the teacher are less likely to provide the parents with feelings of self-worth.

Communication

The way in which professionals communicate with parents may discourage true participation by the parents and can even prevent the team concept from developing. Innovative ways must be devised to open the lines of communication. The typical school-home communication process usually consists of a form letter with small type and big words. Lots of educationese and legalese may be thrown in for good measure. This type of information may remind parents of the times the school system called them in for either their own or their child's transgressions. Some of the most obvious "turn-offs" for parents are:

1. Sending the information home with the student without a guarantee of receipt.
2. Using a technical form letter with small print educationese, lots of blanks, and no way for the parent to respond.
3. Failing to send a follow-up to the first letter.
4. Assuming the parents don't want to participate, thereby activating a negative response in everyone.
5. Using big words to express simple thoughts.
6. Having no personal or meaningful contact with the parents before their participation is requested.

7. Relying on the professional to contact the parents--setting up the "us - them" relationship.
8. Not looking at the parents as whole people with valuable skills and knowledge.
9. Failing to establish a social groundwork that will set everyone at ease.

Possible solutions:

1. Using a letter containing no educational jargon, which simply requests that the parents come in for a short meeting to help plan the child's program.
2. Using simple English instead of educationese. Educationese is used by educators--it isn't the language of the rest of the world.
3. Using a tear-off sheet so the parent has a convenient way to respond, including a self-addressed envelope if the budget permits.
4. Trying to personalize the meetings. If parents don't respond to the first note, send home short handwritten notes along with a response card.
5. Trying a friendly telephone call to ask parents to participate, if there is still no response.
6. Helping the parents understand the educational system. All professionals are "purported experts" in their field, but most parents don't know the school system. As a matter of fact, it takes a long time to learn any system, and professionals can help to speed the learning process.

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7. Encouraging the parents to ask questions, and listening to what is being said. People are afraid of what they don't understand and may feel foolish asking questions. This situation should always be avoided.
8. Using paraprofessionals to initiate the communication if possible.
9. Helping the parents by sending information home ahead of time so they can be prepared for the meeting. Parents won't know all the "ins and outs" of testing, assessment, and programs--especially if they are presented on the same day, but at least they will feel more at ease.

Most of these solutions may take time in the beginning, but if schools want parent participation, they need to build effective ways to gain the parents' confidence in order to build a cooperative spirit.

Some Positive Thoughts

The watchword for both parents and professionals who work with children is openmindedness. The child's rights should be the prime concern in all discussions between the parents and the school. Parents must feel free to get ideas and opinions from professionals and nonprofessionals. They must be encouraged to go out and look at programs. During all parent-professional conferences, everyone must be on equal ground and must learn to work together.

Parent involvement is vital in the areas of assessment, IEP development, and program placement. No child can be excluded from school because of a

handicapping condition. Professionals must remember that there is no such thing as a waiting list, and they must assure the parents that an appropriate program is possible. Wise professionals will encourage the parents to express their opinions and concerns and will share their own. If the professionals and the parents feel a program or line of action is right, it probably is. Both parents and professionals must learn to share and trust their reactions.

Parents and the public school system must work together in the interest of the child's education, happiness, and physical and emotional well-being. It can be done. It has been done.

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Parents and Professionals

Diane J. Lipton

When I was asked to write about my experiences as a parent of a disabled child and parent relationships with professionals, I was overwhelmed by the task. In nearly ten years since the birth of my daughter, Chloe, I've had contact with scores of professionals in as many circumstances. They have looked at her, worked with her, and written endless reports about her. In my work as a special education advocate assisting other parents of disabled children, I've had contact with additional sets of professionals who work with other children with a wide range of disabilities. Working with parents and advocates to effect changes and influence local, state, and national policy and legislation has added yet another layer of professionals, the administrators and bureaucrats who make the determinations about what our children really need. To try to generalize

about these people, to assume that my personal experiences are typical, that my feelings reflect some typical response seems somewhat presumptuous. I can say with some certainty, however, after years of parent meetings and close relationships with other parents, my experiences are definitely in the ballpark.

The reality of my daughter's being severely disabled has, of course, had a resounding impact on me in many ways. It's forced me to look into myself and at my relationship with the rest of the world. It's required the development of skills and strengths in areas that might not have otherwise developed. On top of that, I have made a career out of being such a parent, especially in the last few years, having jobs related to disability and special education issues. This convergence of my personal and work lives has forced me to examine the nature of my interactions with specialists and to try to understand the tension that often exists between parents and professionals. While we have been luckier than many in that my daughter has worked with some excellent teachers, physical therapists, and a few others, the tensions almost always exist to one degree or another. In some cases the tension escalates into irresolvable conflicts and battles. This degree of escalation is probably more common between parents and administrators than with direct service providers, but not always.

As I see it, the tensions arise from two primary sources of misunderstanding and ignorance. One arises from the lack of input from parents to professionals about the subjective experience of having a disabled child, how parents feel about themselves and their children. The second source arises from lack of input from disabled adults about the experience of being disabled in our culture, the assumptions and stereotypes which further handicap disabled persons, and suggestions of how professionals can truly help.

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The Parent Experience

Not a great deal has been written by parents of disabled children, especially for the benefit of professionals who work with or train those who work with our children, and such input is rarely solicited. Parents, in general, are asked to participate very little, if at all, in training programs, either at the university level or in inservice training sessions for people in the field. School meetings are focused on the children. Consequently, professionals rarely have the opportunity to understand the impact of having a disabled child on the parents and family. Nor do they really understand how the parents view their child or what the needs are beyond the immediate school environment. Consequently, myths and assumptions abound regarding the emotional effects of having a disabled child--parent expectations, parent and family needs--assumptions that often don't fit for a particular parent or child.

The textbooks document the so-called stages a parent goes through in learning that his or her child is disabled. While the stages, of course, have some validity, the ways in which a parent copes with the news and with the child are greatly influenced by all of the parents' prior experiences, and their personalities in general. For example, my activism in the field of special education, particularly in my local school district, has been blamed on my extended and excessive grief about having a disabled child. It's as if I were not a person with my own mode of coping or with any strongly felt values prior to or separate from having a disabled child. I don't deny that I may be partly motivated by some deep feelings of guilt or grief, but who I am and how I got this way is more complex than that. Moreover, the pseudopsychology some professionals engage in is often used to cloud the issues; whether

it's grief or something else that motivates me is irrelevant to whether or not my child requires a particular service. The result of all this psychological theorizing, subtle as it may be, is that parents begin to feel victimized by professional and cultural stereotyping. And victims become defensive, which further complicates interactions between parents and professionals.

And then there is the final textbook stage that the healthy parent is supposed to achieve: the stage of acceptance. I've never been too clear about what that means, and I rarely hear parents use those words. The acceptance stage seems to be more of a professional concept. Maybe I'm expecting too much from the word "acceptance" or maybe too little. At first, I thought it meant that I accepted my daughter's being disabled and I quit wishing that she weren't disabled or something she's not. Later I thought it meant accepting that she's going to get a raw deal because she's disabled. Whatever it is, it's one of those fairly useless concepts that makes parents feel that they are entirely responsible for adjusting to a world in which disabled people are viewed as something less than whole and human, and that unless their child can easily fit in, he or she will have to "accept" seclusion and isolation. Since I long ago rejected this interpretation of acceptance, I basically had to develop my own understanding of what and how much I need to accept. The best way I can describe this understanding is by giving some personal background about myself and my experience.

My childhood and upbringing did little to prepare me directly for raising a disabled child, although it must have given me some feeling that bucking authority was not the worst thing in the world. I grew up in New York City in a middle class Jewish family and neighborhood. There was a strong emphasis on education and on the belief that

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education is the key to success, independence, financial security, and personal satisfaction. I came to California to attend the University of California at Berkeley, attracted to the political and social activity of the University and the Bay Area. I studied English literature, mainly because I enjoyed reading novels. After graduation, I married, and my husband and I traveled in Europe for a year. When we returned, I felt compelled to choose a sensible career, and so became a high school English teacher. Throughout the 1960s, living in Berkeley, I was involved in various social and political movements, mainly the civil rights and antiwar movements. My involvement with these causes was not so much motivated by rebellion from my family and upbringing, but by the liberal and humanistic values imparted to me by my family and by some identification with scapegoats via the persecution experienced by my parents and relatives. For me, I had a sense that my life could go in pretty much any direction I chose and that I had done all the things that were supposed to open up choices and give you at least the illusion of having total control over your life.

- Disillusioned with the quality of public education, I took the opportunity to leave teaching when I became pregnant. Circumstances arose during my pregnancy that resulted in a brutal realization that my life might not follow the expectable course I had always assumed it would. At about six months, I was told that I was pregnant with triplets. No one knew how or why. The triplets, three girls, each weighing two and a half pounds, were born when I was seven months pregnant. One was stillborn, one lived for a day and a half, and the third survived, my daughter, Chloe. The birth of triplets is a miraculous event even to hospital personnel. The delivery room was packed with doctors, nurses, my husband, and a score of observers in a glassed-in observation room. I was fully awake and alert. The

course of my life from that moment on seemed totally in the hands of these professionals. Needless to say, I felt like a freak.

Those first few weeks were filled with the most intense emotions, sadness, and constant worry but also elation that Chloe was still alive. She spent eight weeks in the hospital, mostly in the intensive care unit. By eight weeks she had survived various medical difficulties, had begun to gain weight quickly, and we were able to bring her home. We felt fortunate that she did not have any respiratory problems. While Chloe was in the hospital, we spent many hours each day in the nursery. I observed her every blink and movement. I noticed slight and barely perceptible differences in the way she moved from the way other infants moved in their incubators. The nurses joked about my observations, saying maybe she would be a toe dancer some day. At no time while Chloe was in the hospital or immediately after her release were we informed about the possible developmental risks and deficits associated with prematurity.

Throughout her early months we frequently took Chloe to the pediatrician and asked why she couldn't hold her head up, didn't sit up, arched her back and, in short, wasn't doing the things the books said she should. Our concerns were minimized by the doctors.

Finally, following a ten-minute examination when Chloe was ten months old, a pediatric neurologist we had never seen before told me that Chloe had Cerebral Palsy. He said she might never stand or walk, but he couldn't yet determine how smart she was, as she "appeared" to be alert and responding in a fairly normal way. I was stunned by the news. I sat there holding Chloe and calmly nodding my head while my legs and hands began to shake. The doctor rose from his chair to open the door for me. Noticing I wasn't getting up, he said I could sit

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there for a few moments and then he walked out. I didn't know what to do. I couldn't sit there all night alone. I went to a phone to call my husband and a friend to come and pick me up. I couldn't drive home. I was offered no counseling, no assistance, and almost no information. The doctor knew nothing about any programs or things we might do. He vaguely referred to physical therapy. When we arrived home, we sat and stared at each other and at Chloe, overcome with confusion and sorrow. The agony of the pregnancy and following weeks seemed endless. We felt totally alone in the world. I mostly focused on how I would tell my family and how I could do this to them. I didn't really know what Cerebral Palsy was. I pushed the image of a wheelchair and metal from my mind. All I had were Chloe's smiles and cuteness to comfort me.

Typically, I flew into action--unable to accept the helplessness. I made calls to the Easter Seal Society and United Cerebral Palsy to find out what to do. They offered very little. A few weeks later, by chance, a local pediatrician treating Chloe for a cold told me about a Development Center for the Handicapped (DCH), which was only a few minutes drive from my house, had an intensive day program for handicapped babies. I could hardly bring myself to use the word "handicapped." (And it wasn't until a few years later that I began to understand the politics of language.)

At about one-and-a-half years old, Chloe began to attend the DCH and received a full-day program and an array of services. The staff was warm, loving, and extremely competent. Parents were encouraged to spend as much time there as they liked, to help out, participate, or just observe. Chloe began to feed herself and sit on a little potty. She began to say "Hi" and "Dada." She laughed a lot and hated to take naps. She was around other babies. I was around other parents. That was the good news.

The bad news was the recurrent trauma of meeting with the experts. There were the doctors who, after observing her for a few minutes, made pronouncements about Chloe's intelligence or possible lack of it, they used her in their lectures to students making prognosis on a child they didn't know, talking about Chloe as if she and I were not in the room. One said she would walk by the time she was four. Another said she would never walk. Some of the experts were kind and tickled Chloe. Some were cold and "professional." Often their words seemed to have no relation to my strong-willed baby. Rarely was I asked what I thought and never what I felt. I suppose they thought that was too personal. I began to dread the "multidisciplinary" team meetings. They were a cross between a post mortem and a Peter Seller's satire on the awkward professional. At the end of the meetings, we were asked if we had any questions. I always felt obliged to come up with a few so I wouldn't look like a total zombie. But rarely did I ask about what was really on my mind, like what happens to kids like Chloe when they grow up, and how she will make sense out of or understand being "disabled." (At some point, my language changed.) I suppose I was afraid to hear the canned answers.

At one meeting I did manage to ask how I could help her deal with being disabled. The psychiatrist jumped in to answer, this being her supposed field of expertise, and said that children with cerebral palsy did not become aware of being different from other kids until they were 12 or 13 years old, at which time they usually sank into a deep depression. I wondered how the hell she knew that. It seemed unlikely to me that a child with Cerebral Palsy who had at least some awareness or intelligence and sensitivity would notice something before that age. Then there was the team of doctors who based everything on head size and whipped out their measuring tapes before they even knew her

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name. After a few months of these experiences, I developed a mistrust of these experts; their judgments often seemed ludicrous and based on so little. And when they finally talked about the future for handicapped kids, the choices seemed so limited. It was either going to be a brilliant career at Harvard or working at the neighborhood "7-11," or living a vegetative institutional existence. While I didn't know what was in store for her, I felt these experts definitely lacked some imagination. Furthermore, I couldn't understand how you could decide such things about any child at age two, let alone a severely physically disabled child.

After obsessively evaluating the opinions of these experts, I decided I had to follow my own instincts about Chloe, take their ideas with a grain of salt, and have confidence in my own feelings. I knew her best, after all. It was Chloe's joy, vitality, and determination that motivated me to fight the assumptions and the labelling which made an object out of her.

During these early years, the internal struggles with myself surfaced frequently enough that they became hard to avoid. I felt, at times, like a failure for having borne a "defective" child, with all the attendant guilt and self-blame despite my rational understanding. My sense of sexuality and femaleness suffered. I felt inadequate as a woman and as a human being. Other mothers had something over me, they knew about things I didn't. For them, sexuality resulted in "normal" children. They took pleasure in watching their children develop in ways that I couldn't. There was an almost constant depression to ward off, which sapped my energy.

I certainly did not buy the religious notion of having been chosen for the challenging task of raising one of God's little unfortunates. In my best moments, I thought I was doing an OK job and

forgave myself for my shortcomings. In my worst moments I felt angry, frustrated, burdened, and deeply saddened. I didn't know how to relate to the rest of world, not even if I should expect my child to be invited to other kids' birthday parties. But the demands of everyday life--shopping and cooking, socializing, buying a new couch, getting haircuts, watching the news on television--afforded some relief and put the ordeal of "adjustment" to the unexpected demands of having a disabled child in some perspective. It offered some relief from the painful image of Chloe struggling through life in a wheelchair.

The ways in which Chloe was just like any other child, throwing toys, hating to go to bed, yelling to get attention, testing limits, did not (in the early years, anyway) cause the degree of irritation that they do for other parents. These were the normal things I expected from a child, they were almost welcome signs. Her smiles and affection, her sense of humor, her delight when she was finally able to turn over gave me more happiness than I have ever known in my life. These things, too, lessened the depression and brought me back into contact with the rest of the world.

To many people who knew me, mainly to friends and people I was close to, I seemed strong. I aggressively pursued services and conscientiously participated at my daughter's center, confronted administrators with unmet needs, and became involved with other parents. I became close friends with a couple of other parents. Their generosity and the understanding that we share has been a benefit I would never have anticipated. I joined parent groups and made cupcakes and jello molds for the first time in my life.

By the time Chloe was about two-and-a-half years old and attending the DCH six hours a day, I decided to

return to school and get a master's degree in rehabilitation counseling, combining my interests in psychology and disability. Rehab counselors work with disabled adults to promote vocational goals and independence. There were very few disabled people in my training program. There was still this dichotomy between us (the Counselor) and them (the Disabled Client), a dichotomy that went beyond the usual professional/client roles perhaps because of a common phobic response to disability. It was hard for me to tell even my classmates about Chloe. When I did, the response was often pity and sympathy, which only reinforced unpleasant feelings about myself. However, when I started to work with disabled adults in my field work training, I began to have new insights into the experience of being disabled, new realizations about the range of career possibilities and about our society's treatment of disabled people.

One of the first clients I visited was a young man with a spinal cord injury and quadraplegia. He was sitting in his house celebrating a friend's birthday drinking beer through a straw. They were laughing and enjoying themselves. I never saw someone in a wheelchair in this informal way, drinking beer and taking care of his friends. I was moved by this scene, maybe because of its mundaneness. Most importantly, I began to see disabled adults as normal people, handling the demands of everyday life as well or as badly as everyone else.

At around this time, when Chloe was three years old, she was sent from the DCH to a school for higher functioning physically disabled children run by the local school district. While I was pleased that her teachers recommended this change and thought she would benefit from a more challenging environment, I found the change from the warmth and protection of the pretty Center on the hill to a more school environment frightening. Had she started in a more

integrated program, where she and I had contact with nondisabled children, I believe the change, any change, would have been less difficult. The isolation, even though relatively brief, had a strong impact on my acceptance of isolation as a way of coping and educating Chloe. Nevertheless I agreed to the change. On the first day of school, I drove Chloe rather than send her on the bus so I could make sure she would be properly received. With some anxiety, I carried her into the building and was greeted at the front door by the principal who, in the most somber tone, informed me that, if Chloe couldn't "cut it" here, she would be sent back to the DCH. I wondered if she (the principal) thought she were running Harvard instead of a school for young children. It angered me to think that on the first day of school other parents do not have to feel such trepidation, but rather view the school as there to serve their children.

This school, which was supposed to provide so much more stimulation for my child, seemed in some ways sadly lacking. The length of the program was three hours a day and, during that time, Chloe received occupational, physical, and speech therapies. Along with recess and snacks, about one hour a day remained for work on independent living skills, cognitive concepts, socialization, and play with other children. Despite the fact that some of the staff were highly competent, what could they do in so little time? Moreover, there were children up to seven and eight years old attending school three hours a day. I talked with a few other parents with similar concerns, and we began to work together, meeting with school administrators, going to our State Department of Education to complain about the deficiencies in the program. We were mostly told that they didn't have to serve our children at all and that we should be grateful for what we had. They claimed that if our kids got more, other children would get less. Although we succeeded in

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getting some important changes, it was a frustrating struggle. I learned one thing--the parents who made the most noise got the most for their children. That didn't seem fair, to say the least.

In 1977 I attended my first workshop about some new law, PL 94-142. I avariciously studied the law and regulations. It amazed me that my own ideas about education for children, let alone disabled children, which appreciated individuality and the role parents should play, were taken seriously and even mandated by the U.S. Congress. Underlying the specific guarantees of the law and regulations were social values entirely consistent with those articulated by other social movements except here they were applied to the rights of disabled children. Ideas with which I was familiar, such as civil rights, nondiscrimination, consent, confidentiality, participation and input of parents and the community, compliance, due process, development of state plans, remedies, maximum integration, and so on, were now being applied to the education of disabled children. Someone else said our kids have rights--that parents have rights. It was going to be a different ballgame at my first IEP meeting.

Learning about the new laws, along with gaining experience as a rehab counselor with disabled adults, I began to notice a marked shift in my feelings about myself and Chloe. I was beginning to see us less as an isolated unit (my husband and I had amicably separated by this time) with our own personal problems and frustrations. The difficulties I had knowing how and where we fit in began to diminish. Living near Berkeley, I saw the heartland power of the disability rights movement growing. There were sit-ins in the federal building in San Francisco by disabled people demanding that HEW issue the new Section 504 regulations of the Rehabilitation Act of 1973, finally guaranteeing civil rights to disabled people. I began to see

that Chloe (and less directly myself) was part of a disabled community with the same interests. No longer did I need to accept our failure to fit in as my own fault or Chloe's. I no longer needed to internalize the defectiveness as my own. Something definitely was wrong with the system, which was going to hurt Chloe and had already hurt me. Seeing this, my expectations for Chloe heightened, not so much in her acquiring skills I hadn't thought possible, although that was part of it, but mainly in terms of not allowing her to be cut off from the world, to have her segregated so that others don't need to be disturbed. She is now, by the way, in a special day class for multihandicapped children in a regular elementary school. A few years ago, I wouldn't have dreamt of insisting that she attend our local neighborhood elementary school. I couldn't have imagined how she could fit in.

I began to see the struggles with the administrators and educational institutions in a more political way. The issue was and is the denial of civil rights for an excluded minority and the overcoming of institutionalized prejudice akin to racism or sexism. The struggle seemed more meaningful within this context, made more sense. It wasn't just the good guys against the jerks. It went deeper than that. It became easier to fight for adequate programs and services, not only because we had the law behind us, but also because the fight became less personal, it freed us to think through strategies and objectives more effectively.

More recently, as a result of a reduction in occupational and physical therapy services at Chloe's school, which we later learned was occurring throughout California, we began a statewide effort to secure these services, which are guaranteed by PL 94-142. We parents and advocates throughout the state managed to influence the withholding of 80 million dollars in federal funds to California until

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state policy and regulations were in compliance with federal mandates (Note 1). It was a thrilling victory, to say the least. Added to the euphoria was the process itself, the collective effort, parents and advocates working together without doubt about our children's right to an appropriate education, including, if not emphasizing, services to increase independence. My sense of powerlessness and helplessness diminished. I hoped that Chloe understood at least a little of what was going on.

Through this statewide effort and present struggles in California (focusing on the need for integrated education for disabled children), my contact with parents and professionals increased. I began to see the tension between parents and professionals in new ways. Few professionals understand the "rights" aspects, or more practically, that the environment has to include and make accommodations for disabled children. The burden is usually on the disabled to prove that they can fit in.

Professionals may understand that educational approaches need to keep evolving, but they rarely focus on how attitudinal barriers can be overcome. The pervasive resistance to change comes not only from personal habits, but from social and economic institutionalization of old habits and prejudices. Professionals, threatened and frustrated by their own inadequacies and the inadequacies of the state of the art, project the threat onto parents. There is a lack of understanding of the role parents can play in breaking down the institutional barriers. Often, toleration of parents at IEP and various committee meetings is mere tokenism. I have noticed though, in the last year or two, parents shifting away from token participation and demanding more meaningful roles. The period of transition from passive and uncertain participation toward a more assertive stance is further along. Professionals are getting used to us.

The Disabled Experience

Perpetuation of erroneous assumptions and prejudices continues, I believe, partly because parents and professionals are seriously handicapped by ignorance about disability. Usually there has been little or no contact with disability, except possibly with aging relatives prior to either having a disabled child or receiving professional training. So both parents and professionals have attitudes and beliefs not much different from those of the general public. And once plunged into the arena, for the most part, they remain ignorant. Parents, through constant contact and sensitivity to their children have at least more of an opportunity to overcome certain stereotypes about disabled people. Professionals, having limited intimate contact, have a harder time overcoming these stereotypes. Professionals who work with disabled kids on a daily basis definitely understand the differences between the kids, their needs, and so on, but being cut off from disabled adults, they sometimes develop goals and curriculum without a clear idea of what the children need to learn for adult life.

For those who don't work directly with the children (like regular education teachers), the gaps in understanding can be and often are horrendous. Sometimes parents and professionals make totally different assumptions about the child's present abilities and future needs and they aren't even aware that these assumptions exist.

As an example, when Chloe was seven years old and about to get her own wheelchair for home and school use, the therapy department at her school advised us to get a manual chair. I thought it would be better to get her a motorized chair she could operate herself, as it took her 10 minutes to cross a room in a manual chair because of slow arm coordination.

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The therapists insisted that she wouldn't be able to properly run a motorized chair, that she was too young, and that a manual chair, although slower and more frustrating, would require more arm exercise. It was clear that we had very different views about the purpose of the chair. To me, a motorized chair meant increased independence, motion and movement in a new way, increased ability to socialize and expore, and a better sense of control over her life. We secretly practiced with Chloe in a motorized chair loaned to us. The therapists were surprised at how well she did with it and finally agreed to purchase a motorized chair. For Chloe, it was the beginning of a new stage in her life, a stage that had been long enough delayed. A disabled friend of mine who was not permitted to use a motorized chair until she was 21 convinced me how important this was for her.

For parents, professionals, and disabled children, there is almost a total absence of disabled role models. Advice, opinions, prognosis, and expectations arise from a vacuum. Most have little or no idea about what it's like to grow up disabled; and few of our children have the capacity to articulate it fully. How many of us at age nine or ten would have been able to describe what it's like growing up in our families, neighborhoods, and schools? Very few. But at least, if you're a nondisabled adult, you can make some fairly reliable assumptions about how life is for your nondisabled child. Or, if you're a black parent, you know what it's like to grow up black in this culture. But being a nondisabled parent or professional, you're really in the dark regarding at least some areas of the disabled child's experiences. Moreover, most parents and professionals are unaware of what's possible for persons with disabilities. It has been well documented that disabled children are victimized by labeling. Once a child is labeled as mentally retarded, expectations drop, regardless of

the child's capacities. On top of this, professionals who are unaware of the degree of independence a mentally retarded person can achieve, drop their expectations even a few notches lower. While parents are subject to the same influences, knowing our children as we do and having to face a lifetime of caring for a dependent son or daughter, we have a greater belief and stake in maximizing the independence.

Furthermore, what is rarely discussed either in schools or at school meetings is how the disabled child understands and copes with being disabled. Every year at my daughter's IEP meeting, I raise this issue and ask what explanations are given to the children about their disabilities--are there discussions about it, how do they feel about having physical therapy, and so on, to the extent that they can express or act out their feelings. If these issues arise in school settings, they are not addressed with parents. And it's no wonder, as it is a difficult area to explain, especially for people who can only imagine what it's like. Perhaps it is such a painful or sensitive area to the adults, like sex, that it gets pushed aside. It's a lot easier to discuss how many colors a child can recognize, how to "manage" and control behavior, or how to teach a child to use verbs like run, hop, and skip, which may be totally meaningless to the child's experience.

These gaps in our understanding can best be overcome by contact and input from disabled adults. Parents and professionals desperately need more information. Our children desperately need more models.

My contacts and friendships with disabled adults have provided a few role models for Chloe and me. Their stories of the failures and strengths of their education have taught me a great deal. Almost

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without exception they have said that segregated education was detrimental, not only academically, but also socially. As a rehab counselor, I have seen disabled adults, both those with mental retardation and those with more "normal" intellectual abilities handicapped, not so much by lack of specific work skills, but because of lack of adequate social skills. I cannot understand why even the most severely disabled children need to be educated in segregated schools. They may require placement in special day classes for most of the school day, but surely there are at least a few activities a day or a week in which they can be integrated with nondisabled children. The only reason I can see for such segregation is to satisfy administrative convenience. I would also bet that most proponents of segregated schools have never spent any time talking with disabled adults about these issues. I would bet that most special education teachers and specialists have never talked at any length with disabled adults about their school experiences.

In the last couple of years, working as a special education parent advocate at Berkeley's Center for Independent Living, I have attended many IEP meetings with parents. I have never once seen school personnel include in discussions or in the IEP itself anything regarding the exposure of disabled children to disabled adults, how they work and live, use transportation, and so on. No wonder some disabled children deny being disabled, or fantasize that their disabilities will disappear when they grow up.

Usually, by the time parents seek advocacy assistance, they have experienced extreme frustration convincing professionals that their children would learn more in an appropriate program or that a particular service will be beneficial. Professionals respond to these requests and concerns

in a variety of ways. Often they assume because they have not seen something work that it doesn't work, or they make assumptions that because a child is not performing a certain skill by a certain age, he or she will never acquire it. When I relate this to disabled adults they often smile knowingly and recount how they couldn't dress themselves or use one arm or hand, but later mastered the skill when motivated to do so, through tremendous effort and drive. Many parents have had this happen--they have seen their child do things the professionals doubted he or she would ever do. Worse still is an administrator telling a parent that a program or service can't be provided because of the financial cost. This does not inspire confidence in the professional's assessment of a child's needs.

While professionals, like parents, are entitled to make mistakes or have differences of opinion about what a child needs, for parents these differences can intensify the frustration because professionals or administrators are in a position to provide or deny a program or service and almost always get their way. This is true even when parents have won a due process hearing or a noncompliance complaint. The child may still not receive the service. So professionals and parents have unequal bargaining power. For parents, this can be the harsh reality that causes dropout, fatigue, despair, or incredible persistence and self-confidence. For the professional, this means that he or she carries a heavy responsibility to make well-informed judgments not only based on expert opinion, but also on the opinions and needs expressed by disabled adults as to what education and other services should be about in light of psychological needs and the skills necessary for adult life styles.

Conclusions

What I have learned from disabled adults and the disability rights movement on an emotional as well as an intellectual level has had a very deep effect on the way I see my daughter and myself. That is not to say that I go through life avoiding painful feelings, that I'm totally guilt free or that I never tire of taking care of Chloe's many needs. But what I have learned has provided a framework for understanding where professionals are coming from and appreciating their viewpoints as well. It has provided a framework upon which to continue struggling to hold on to hard-won laws and regulations and to insist on full compliance.

I now recognize that the struggle to maintain and expand vital programs and services goes beyond money (the usual excuse). There is a substantial difference in the way I see our culture's responsibility to accommodate to the needs of the disabled to allow full exercise of fundamental rights. To the degree that professionals insulate themselves from parents and the adult disabled community, they are able to avoid seeing the issues from the "rights" perspective and can continue to impose stereotyped ideas on our children. They can continue to see parents as having "unrealistic expectations." These preconceived assumptions make things simpler. It allows professionals to feel either that they have the answers or that there are no answers to be had. I think neither is true.

Input from parents and disabled adults can be elicited in many ways. Disabled adults should be employed as teachers, aides, and other specialists to provide role models for disabled children and to educate parents, regular education children, and professionals. Parents and disabled adults should teach and participate in professional training

programs. Disabled adults should be included in parent groups and sit on local and state advisory committees. In short, parents and disabled adults should work together and be included in all facets of program planning and implementation. Decision makers should work with our children directly. I've often thought that if our local administrators spent one weekend with our children, their views of parents and disabled children would radically change.

For me, disability no longer means the personal disaster I once assumed and felt it did. It does not need to limit enjoyment and active participation in life, especially community life. And more important, one does not have to be a disabled hero to achieve that participation. But we have a long way to go in demystifying disability and breaking through the attitudes and beliefs that still handicap us all.

I have offered some ideas of how to break down the tensions and conflicts between parents and professionals. This is especially crucial now when all that's been achieved by and for disabled people is being severely threatened by the political process. For the future, exposing nondisabled children to disabled children and adults may be the answer. After all, today's nondisabled children will be the legislators, parents, and professionals of tomorrow.

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Reference Note

1. Letter from Edward Martin to Wilson Riles, January 18, 1980, page 3.

Parent Perspectives About Professional and Parent Cooperation

Marie Peters
Margaret M. Noel

Along with the joy and challenge of raising children, all parents are faced with parenting tasks that lead to stress. For parents of young children with handicaps, those tasks are often joined by additional stresses. Typically these parents feel inadequate in coping with the handicapping condition, and often must turn to professionals for advice and guidance. The interaction between parents and professionals, however, is frequently ineffectual, debilitating, and at times even professionally irresponsible (Berger, 1981; English & Olson, 1976; Michaelis, 1980; Rutherford & Edgar, 1979; Turnbull & Turnbull, 1978).

There have been numerous explanations for the poor state of parent and professional communication. Even though there are seven million children and at least twenty-eight million adults with mental or

physical handicaps in the United States, our society has typically awarded the responsibility for meeting the challenge and problems of the handicapped to the individual or his or her family (White House Conference, Note 1). In addition, universities have consistently failed to train future professionals in effective communication skills. Without this training most professionals find it difficult to communicate effectively with parents (Kroth, Note 2). Fear, due to insufficient knowledge about the client and/or the law, is another reason given for poor communication between professionals and parents. Both parents and professionals may be anxious and even embarrassed by their assumed or real lack of knowledge about the nature of the child's handicap as well as the resources available to help the child. If fear is coupled with guilt feelings, it is quite possible that defensive or evasive behaviors on both the parents' or professionals' parts may block a positive communication pattern. Lack of trust between parents and professionals is the third, and perhaps most important reason given for poor communication and cooperation. Trust is a fundamental requirement for any positive relationship, and it is difficult to establish. During a series of interviews with parents of handicapped children, the authors were frequently confronted with a lack of parental trust toward professionals. Yet, it appeared that this lack of trust was due neither to the parents' previous bad experiences with teachers, either as a parent or student, nor influenced by the current trend within our society to blame the public schools for many of society's problems. Rather, the parents explained that their lack of trust toward professionals developed gradually. After many unsuccessful attempts to convince the professionals to "listen to my side of the story," the parents "gave up trying to be the nice guy and started to fight the system." A majority of the parents came away from early interactions with professionals with

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feelings of guilt, helplessness, anger, and rejection. As these feelings evolved and strengthened, the professionals and parents became adversaries rather than partners.

A basic assumption behind the current trend to improve parent and professional communication is that it will enhance the child's opportunities to obtain a meaningful and appropriate education. This assumption has been with us for many years. It was during the 1950s that James L. Hymes wrote one of the first books on home-school relations, which illustrated the interdependence between home and school. In the 1960s parent involvement became a major focus in educational research (Bloom, 1964; Hunt, 1961; Skeel, 1966) and subsequently in federal programs. Head Start, Home Start, and Follow-Through, which build upon the concept of partnership rather than isolated intervention, reflect the belief that cooperation among parents, schools, and agencies is necessary to produce lasting change in education (U.S. Department of Health, Education and Welfare, 1974). In 1978 Public Law 94-142, the Education for All Handicapped Children Act, firmly established the importance of parent involvement. These developments have shaped our thinking about the importance of professional and parent cooperation. The fact remains however, that many parents do not feel that they are an equal partner when it comes to planning their child's educational program. Mandates, research results, and parental demands are not enough. Unless professionals believe that a close cooperation with the parents will improve their ability to understand and plan for children, it will be unlikely that they will expend the energy necessary to involve parents actively. Professional awareness of the need to work with parents is essential.

This chapter presents the reflections of twelve parents of handicapped children who have been

actively involved in obtaining appropriate educational situations for their children. The major focus is upon the parents' experiences when interacting with all types of professionals, (educators, psychologists, medical doctors, physical therapists). The aim of the chapter is to describe the present condition of parent-professional communication and cooperation, as described by these parents, and to present some practical suggestions to professionals and other parents of handicapped children which may improve future interactions.

The information was gathered from structured interviews. The parents who were interviewed included fathers and mothers ranging in age from approximately 25 to 55 years, from different occupations, geographic locations, and life styles. Their children included those identified as learning disabled (minimal brain dysfunction, dyslexia and perceptual handicaps), seriously emotionally disturbed, mentally retarded (both mild and severe) and physically impaired (cerebral palsy, spina bifida).

The interview was designed to gather answers to five questions concerning parent-professional communication and cooperation. The first question dealt with the manner in which parents were informed of their child's handicapping condition, and their reactions regarding the quality and usefulness of the information. The second question referred to the nature and quality of follow-up assistance that professionals offered to the parents. The third question asked the parents to describe the actions they took to help their children once they decided the professional advice and assistance was inadequate. The fourth question was designed to tap the major concerns parents have had or currently have about their child's educational environment. Finally, the parents were asked to offer their advice to professionals and other parents regarding

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ways to improve future communication and cooperation between parents and professionals.

As parents responded to these questions, the importance of parent and professional interaction became evident. The extent to which parents became a part of the educational process for their children was dependent to a large degree upon the extent to which educators were committed to the concept of parent involvement and were willing to allow the parent to be involved.

Discovering the Handicap

For each of the parents the news of their child's handicapping condition(s) came in different ways and at different points in time in their child's life. Two parents knew their child was handicapped at birth, while three parents knew something was wrong during the first months of their child's life. Although the parents of the two children diagnosed as seriously emotionally disturbed were aware of problems very early, the children were not diagnosed until three and seven years of age. For the children with mild handicaps, the period of ambiguity was longer. One mother suspected learning problems when her daughter was in the second grade, but the school would not provide additional assistance until the child was academically behind at least two grade levels. Actual assistance to this child did not materialize until the fifth grade. The four parents of older students, identified as learning disabled, suspected problems during the primary school years, but actual diagnosis of a learning problem did not occur until the sixth, seventh, or eighth grades.

The descriptions of the varied ways parents learned about their children's handicapping conditions characterize the doubtful and/or speculative nature of many diagnostic procedures. Although the parents expressed unhappiness about this period of uncertainty, at the same time they displayed an amazing capacity to endure and draw upon their inner strengths during this time of doubt, even over several years.

None of the parents was satisfied with the interactions they had with the professionals who were involved in the diagnosis of their child, neither were the parents satisfied with the type of information provided at the time of diagnosis. One father reported that the doctor said, "Your child is handicapped, so let her set her own pace and don't push her. If you have any questions make an appointment in about a week." The doctor then left the room. When the father was asked what information he would have found helpful, he replied,

Maybe I couldn't have absorbed any technical information, but I would have appreciated a handshake or a pat on the shoulder and an opportunity to have a cup of coffee with the doctor. It was devastating to be left all alone with the mysterious description of "handicapped." I felt so sorry for my wife, all that work, love, and energy and for what?

Considering the reactions these parents described, it is very unlikely that parents can integrate a great deal of information at the time of diagnosis. Guilt, loneliness, fear, shock, frustration, and confusion were the most frequent descriptors the parents gave when recalling their initial reactions to finding out their child was handicapped. One mother said, "I just kept wondering how I had caused this mysterious problem that had no cure." She expressed fear of the unknown and kept asking

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herself, "Would he ever walk, have friends, be happy." When describing his feelings of shock one father said, "Nothing in our past had prepared us for this experience. We didn't know if we had the energy or money to even keep our daughter alive--the never-ending chores--the disbelief that this could even happen and least of all happen to us."

Nearly all the parents described some feelings of frustration at the time of diagnosis. Most of the frustration appeared to be a result of a lack of any concrete and useful advice from professionals. One mother said "I knew I had to do something but I didn't know what." Uncertainty can produce feelings of anxiety, as indicated by the words of one mother: "I was so frustrated, worried, and confused. I was afraid that I was not doing everything possible to help my son, yet I didn't know what was right, and it appeared as if the teachers didn't know much more." Another mother put it this way, "I knew I had to do something or else nothing would happen."

The parents of mildly handicapped and seriously emotionally disturbed children voiced more anger toward the professionals, especially counselors, psychologists, teachers, and principals. This seems natural. After all, they had been living with ambiguity for many years. In each case the parents repeatedly contacted professionals in an attempt to help their child, but with less than positive results. One mother described her anger at the school by saying,

As early as the second grade my son would come home crying and vomiting, probably due to low self-esteem and/or peer problems. He hated school and I was unsure how much muscle I could put on the school. The whole process was agonizing to the point that I think my son was "school battered." Even if they could somehow

send him to Harvard it wouldn't make up for the humiliation he suffered at the hands of insensitive teachers.

Anger is usually combined with personal guilt. Feelings of guilt and fear are obvious in one mother's description of her reactions to finding out her 15-year-old son was learning disabled. She recalls,

The teachers kept implying that he was just lazy and inattentive, and if we would just do more with him at home everything would be fine. They kept blaming us for his problems. Finally they get you to believe them (even though down deep you doubt it) and then you start jumping down your kid's neck. You tell him he just has to try harder. Well, this goes on for several years and then you have him privately tested after talking with a friend, and find out he has a legitimate learning problem. This causes all sorts of guilt reactions. You feel guilty that you haven't supported your son--that it took so long--that your child has gone through all the torture of failing and feeling rotten, and it wasn't even his fault. And on top of that, his own mother--me--I didn't even support him through the whole process. That really hurts. I still haven't gotten over those feelings.

Along with anger and guilt, the comments of parents of the mildly handicapped reflect a considerable amount of despair and helplessness. One mother recaptured these feelings when she said,

I really knew my daughter was sharp as a whip and I couldn't understand why she wasn't learning. I kept asking myself why the teacher, counselor, or psychologists couldn't shed any light on the problem. If they don't understand or know what to do, then who could I turn to for help?

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Another mother said that she felt desperate and helpless during the gray period before her son was diagnosed as dyslexic. She said she

felt ignored and talked down to by the professionals. The principal in particular had a superior attitude and somehow made us feel as if it were all our fault. We could never find out why we caused the problem or what we should do to make things better. I kept asking myself, "What was wrong and what would happen?"

A mother of a seriously emotionally disturbed child said,

I sought out information about his condition and tried to find the proper treatment for him. We also looked at ourselves, our environment, and we have tried to make changes accordingly. I have found that discussions with doctors, relatives, friends, pastors, etc., is almost impossible. People are afraid and repulsed and do not want to hear.

When we asked the parents to describe the kind of information professionals should be giving parents, the answers were quite uniform. The parents wanted, for the most part, honest, concise, and useful information. They wanted a chance to learn the terminology, to be given some practical advice directed toward immediate problems, and an indication of the long-term impact the handicapping condition would have on their child's life. But the parents also talked about the manner in which the information should be transmitted.

It would have saved a lot of pain and perhaps meant more rapid progress if we had been treated as adults. We would have liked it if the terms they were throwing at us had been explained. Professional honesty and candor would have

increased our level of confidence in their competence.

was one parent's response. Respect was another term frequently used by the parents:

Why can't teachers realize that no matter how well informed they are about the child, the parent still knows more about their own child than any one else in the world. Why can't teachers accept that this information might be very important?

Unquestionably, it was upsetting for all these parents to learn that their children were handicapped. Feelings such as guilt, loneliness, fear, shock, frustration, despair, confusion, and anger underscore the fact that having a handicapped child can be a very chaotic experience. Their comments more than suggest that the aftermath of learning your child is handicapped is devastating.

Follow-up Assistance from Professionals

How effective are professionals at offering assistance or facilitating a cooperative partnership with parents of handicapped children once the child has been diagnosed as handicapped? From our sample of parents the answer would have to be: not very good. Eight of the twelve parents felt they had not received any follow-up assistance from professionals, and in some cases they felt the professionals were working against them. The remaining four parents said one professional had offered some assistance, such as making a referral to another specialist or, in three cases, a suggestion that it might be wise to have their child tested for purposes of institutionalization at a later date.

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Two comments suggest that these parents may not have been very assertive in their requests for assistance. One mother, who did not receive assistance said, "I was embarrassed to call the doctor, after all, it must be my fault and maybe they would tell me something else was wrong." The same feeling came through in another parent's comment, "We had nice doctors, but they were too busy to help us and we didn't really know what to ask of them."

However, the more assertive parents did not seem to have much better luck in receiving follow-up assistance with their respective professionals. As one father put it, "After about three months of bickering we finally got a diagnosis of cerebral palsy, but that was all. We didn't get any recommendations. They were good at treating the medical problems, but that was it. Of course, this was twenty years ago, so it's probably better now." This father's optimism does not seem warranted when one examines the comments of other parents who have recently had their child identified as handicapped.

A mother of a learning disabled boy said the follow-up assistance varied from teacher to teacher, but there was always a great deal of "passing the buck." This mother recalls the following incident:

The counselor would tell me to talk with the math teacher, and the math teacher would tell me to talk with the language arts teacher, and she would say I should really talk with the special education or physical education teacher. It seemed as if they would all make promises but never delivery. It was almost like a comedy of errors. One teacher even forgot the appointment, and when I found him he said, "Oh, I didn't think you'd come--most parents don't care."

This mother recorded 72 phone calls to the school over a period of three months..

Not only was there a lack of assistance on the part of professionals, but several parents also reported that these professionals lacked an understanding of the child. This is highlighted in the following comment:

I felt like they were holding back some information and it wasn't good. I really wanted some encouragement and understanding. When I did succeed in getting a conference with the teacher, she didn't seem to understand the problem and I felt as if she wanted to ease out of a tight bind. I'm not a very assertive person, but I felt my daughter needed more individual attention and some simple praise for all the progress she had made. It wasn't enough for her mother to tell her she was doing well. She wanted to hear it from the teacher. But I couldn't convince the teacher that this was important. Instead, when my daughter would get stuck or couldn't keep up with the other kids, the teacher blamed it on my daughter rather than on the type of work she was assigning or on inadequate instructions. I know my daughter was working hard, sometimes three to four hours every night, but the teacher didn't seem to care. After about six months of that my daughter started getting headaches and an upset stomach. I was fit to be tied.

Administrators were also found lacking when parents described follow-up assistance. One mother said, "I find that in the area of education the problem is not with the teachers, but with the administrators, most of whom are ineffective or unwilling to help. They are too concerned with their images, budgets, and careers to care for the children." Another parent pointed his finger at the university administrators and researchers. He said,

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The people who work directly with kids are pretty good. But once you take a step away from the kids there seems to be a lack of understanding and the bureaucratic instinct take over. Sure there are too many unqualified educators, but that's true in any field. I can understand that. But I can't understand an administrator who lets research results and training programs come before the welfare of the kids in the program.

We suspect that the professionals can speed up the helping process by listening and by encouraging the parents of handicapped children to seek or accept assistance. This positive outcome, however, is probably contingent upon the presence of at least three conditions: 1) the parents clearly perceive they need help and are ready for it, 2) assistance is offered by someone they can trust, and 3) a formal line of communication is established to maintain the partnership.

Coping Strategies

It is quite clear from the previous section that professionals were not offering much follow-up assistance to these parents of handicapped children. Where assistance was provided, it was often done ineptly. When examining the total responses to the interview, it appears as if the greatest amount of assistance or help for parents came from their spouses, friends, and from their own natural inner strength and love for their child.

Nearly all of the parents reported that they read "fiercely" about their child's handicapping condition in hopes of finding "at best a cure or at worst a prognosis about what lies ahead." The

parents valued this information because it reduced the ambiguity and allowed them to plan for the future.

As would be expected, parents of severely handicapped children typically begin to reach out and search for help sooner than parents of children with mild handicaps. Although they all suggest that the first months after learning their child was handicapped was a fragile time, they quickly assumed the active role of searching for the services necessary to meet the needs of their children. During this time they contacted other parents of handicapped children and "talked and talked and talked with other parents." This communication helped them learn more about their child and provided them with some ideas regarding available options. The search for the "right" program took them in many directions. They visited many different schools and centers, joined parent groups, wrote letters to school districts, state departments of education, and federal representatives of special education, and fought for evaluations in order to justify an educational program for their child. If their child was lucky enough to be accepted into an appropriate educational program, the parents often had to locate trained persons to run the program and find the money to pay them. As one mother put it, "I fought a long battle with the system, and still don't know who won." Most parents logged the phone calls and visits they made and the letters they wrote while continuing the search for an appropriate educational program. These records are impressive accounts of perseverance and courage.

One mother went back to the university and obtained a Master's Degree in Special Education and another studied various school curricula in order to adapt them to her child's needs. At some time, all of the parents worked directly with their child in order to "prove" to the various educators that their child

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could "learn." Four of the five parents of severely handicapped children eventually entered into some form of litigation with all the accompanying complications (Noel, 1982).

Parents of mildly handicapped and seriously/emotionally disturbed shared many of the same coping strategies as described above; however, a lack of precision in identifying a cause for the problem(s) associated with learning disabilities and seriously emotionally disturbed handicaps usually extended the length of time before an official diagnosis was made. During the primary school years all of these parents reported that they had worked intensively with their children across all academic subjects. Usually they would focus upon spelling words, math problems and reading. It was not unusual for parents to spend from one to two hours a day in structured learning activities with their child. One mother, who had been a primary school teacher, described the homework sessions with her daughter.

It was exhausting. We were both so tired and I often became very discouraged when I looked at her sad face. It seemed like so much had to be accomplished. I'd try to be optimistic and rewarding, but she didn't really believe me when I praised her, after all, I was just her mom. Sometimes I would become so frustrated with her and myself that it was impossible to hide my disappointment when she couldn't remember something we had worked on for so long. I got angry a lot and was jealous of mothers with kids that learned easily. I knew my daughter was working just as hard as the other kids, but she wasn't getting any credit for it. I also got angry at the school for shoving everything on my shoulders.

Parents of mildly handicapped children relied a great deal upon the "hidden network" of parents with handicapped children. Entering into the hidden network was usually informal and often by accident. A mother would be talking to a friend about her son's or daughter's problem, and the friend would suggest that she call another friend who had a similar problem. These informal contacts usually led to more formal arrangements. For example, each parent interviewed had contacted parent groups in the community, read available literature, and made numerous visits to the school. The visits to the school were, however, often debilitating. One mother said that "In eleven years, only once did I feel that a teacher cared for my son. That teacher said she would help and she did. I'll never forget her." Another common result of the hidden network was a raising the parents' awareness level of their rights as parents of handicapped children. Four of the five parents with mildly handicapped children had their children tested at their own expense in order to convince the school district that it had a responsibility to provide appropriate programs for them. Each case history reflects the determination of these parents to solve a perplexing and painful problem. Solving the problem meant many contacts with the school, extra homework, sending for activities at which their children could succeed in order for them to maintain a certain amount of self-esteem, meeting with other parents, and in some cases, engaging in due process.

The experiences described by parents of severely emotionally disturbed children reflect similar struggles. The coping strategies used by one mother certainly suggest determination, but also despair. She writes,

I learned to recognize when I was being put off, put down, and when I was being lied to. Unfortunately, recognizing it is easier than

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doing something about it. The feelings of helplessness and heartbreak are overwhelming and serve to reinforce the intimidation. When your child's future is at stake and all you encounter are uncaring, incompetent, and deceitful people, you feel helpless and want to give up after months of this kind of treatment, not to mention after years. I have been depressed many times, but thank God I must have some fighting spirit left or perhaps it is because (my son) is my only child. But I believe I go on because he shows so much courage and that gives me strength.

This same mother described how she and her husband tried to support their son and continue to work with him.

I began to read to (my son) when he was very young, 1-1/2 to 2 years. He showed no signs of understanding, but I kept right on reading and I think that he was indeed absorbing and has grown into a lover of books and a sponge for soaking up information. I spent perhaps three to four hours a day during the early years. When he was in nursery school, we spent at least one to two hours in the evening reading, listening to music, and playing. After a while I spent less time reading to him because he was reading to me. We did have many talks, and that time I really treasure because as his disease progresses it becomes more and more difficult to make real contact with him. We do things with him now like scouts, and going to museums, movies, arcades, and concerts. We enjoy these activities very much for our own sake as much as for his benefit. I was den mother for his cub scout troop, and my husband was a leader. We are on the committee of his scout troop, and take an active part in its functioning. He likes our participation but does not hesitate to ask us to step back when he needs or prefers to

be on his own. Having our child, with his problems, was a factor in our decision not to have more children. We felt and still feel we have a responsibility to do the best we can for him. We try to keep a balance, and sometimes it is hard, as it would be for any one-child family. We chose to have our son, he was not an accident. So we are ready for the responsibility and we accept it. We enjoy every stage of his development, we savor every phase--raising a child is what we wanted to do. Yes, there is pain when we think about his future--Will he be able to have a life of his own? Will he be able to marry? Should he have children? Will we miss out on being grandparents? These things are painful to think about. But we have him now and we try to live now, we do the best we can and try to have as happy a life as we can NOW.

Parent's Concerns About the Educational Environment

For parents of severely handicapped children the first hurdle is to get their child into a program. Thereafter the concerns vary according to the specific needs of the child, but an underlying wish remains. These parents want their child to be in "a normal environment with normal kids." One mother chose an educational program with fewer resources in order that her son could "go to assemblies, eat in the lunchroom, walk with nonhandicapped children, and share recess" with the other kids.

A second major concern shared by all parents of handicapped children, regardless of severity of the handicap, revolved around the teacher. The parents wanted a teacher who would work cooperatively with

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them in order to develop an integrative and meaningful program for the child. A father of a severely handicapped child said, "A good teacher can save everything." The same idea was voiced by a mother of a mildly handicapped junior high school son, when she said, "The teacher is everything. A wise and understanding teacher is the most important thing. Without one you have nothing and with one you don't need anything else."

The teacher's attitude and manner of working with the child and parents was another frequently mentioned concern. A frequent comment was "I would give anything for a teacher who would show real interest in my child and respect for my feelings."

Providing an "encouraging environment" was another central theme. The parents of the mildly handicapped children talked more about this concern, especially in connection with their child's lack of self-esteem. The following quote reflects this concern:

I only want the educational environment to build up my daughter's self-confidence and not continually give her the hidden-message that she is dumb. This can probably be more easily accomplished with a smaller class size and an understanding but demanding teacher. I know everything goes hand-in-hand, but the main thing is that these kids be given back some self-respect. A competent teacher can foster self-esteem in any child. I've seen it happen with my daughter.

Another mother says she wants "A teacher who will try to get inside my child's head and try to find out how he is feeling and perceiving things. Kids want to make adults happy--why can't teachers believe that and take the child's part at least once in awhile?"

One set of parents of a severely emotionally disturbed child said they wanted "safety and quality" in their child's educational environment. The mother wrote that "Our greatest concern was and is for his safety. We talk to parents who have had their children injured in school." She continued by describing several instances whereby children were injured and no action was taken to correct the situation. After safety, this mother wants "an adequate education that will equip him to function in life."

Interestingly, most parents did not mention relationships with nonhandicapped peers as a concern. Parents of severely handicapped children primarily wanted their children to have an opportunity to interact with normal children, but they did not elaborate about what type of interaction they desired. Only one father said he was somewhat concerned that there might be problems between the handicapped and normal kids and that his son might be "just as happy in a segregated school." Parents of mildly handicapped children included stories of how their child had been teased, beat up, and generally humiliated by normal children, but for the most part they felt the teacher's attitude and manner would be the best defense against negative peer interactions.

In essence, all of these parents wanted a supportive environment with a well-trained teacher who was willing to engage in cooperative planning with them to ensure a meaningful program for their child. Unanimously, the teacher was seen as the critical figure in the educational environment. An ideal teacher, according to these parents, is one who respects and listens to the parent and offers encouragement along with honest and open feedback about the child's progress. These parents also believe that administrative support of these types of teachers is necessary in order to facilitate a

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well-functioning and nurturing learning situation for handicapped and nonhandicapped children.

Advice to Professionals

Be Frank and Open

In response to request for advice, the parents who were interviewed strongly advised professionals to be "honest with parents and stop making excuses--just tell it like it is." This desire to have the professionals lay the facts on the table in an open, direct, and frank manner was the most frequently mentioned recommendation. Excuses or vague explanations of the problem are often interpreted by the parents as an over-protective attitude or simple evasion of the truth on the part of the professionals. Parents felt that when this happens two things may occur: 1) the parent's adjustment to the problem may be blocked, and 2) the child's progress may be delayed. Hymes (1974) has been encouraging teachers to be open and frank with parents for a number of years. He said,

The parents you deal with in your home-school relationships are adults and adults can take a fact. They can make a comparison. They can reason. Your big job is to give them enough to think about. Don't undersell today's parents. Don't underfeed them. Give mothers and fathers the chance to hear, the chance to see, the chance to think, the chance to speak and to contribute that adults deserve. (p. 35)

Listen

Professionals were also encouraged to "listen to the parents and accept that they (the parents) might know more, or at least something else about the child that might be helpful." One mother said that she thought it was imperative that teachers "really hear what parents are saying. Look objectively at the information they are giving you and don't put so much emphasis on the belief that the parent is too biased to know what is going on with his child." The same theme is reflected in the following quote:

Trust parents, help us understand what we don't know but listen to us, don't discount us because we are only parents. I have had the experience of trying to convey something to a professional and have him not trust my perceptions, thus causing a real trouble for my child. This could have been prevented if he had believed me and given me advice based on the facts.

Another mother summed it all up by saying "Just remember that I've been with this little kid since conception and I love him with all my heart, and I want the very best possible for him, not me."

Don't Be Afraid to Say I Don't Know

The parents were not critical of professionals who didn't have all the answers to their problems. They appreciated an honest "I don't know" response and deeply resented professionals who tried to "fake it" through. A team approach can often be fostered when both parent and professional join forces to solve a problem. The following comment illustrates this point: "I couldn't believe it when my son's reading teacher said 'I really don't understand it, but let's delve into this a little further.' I felt so relieved and grateful after that conversation."

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This mother had already indicated that previous professionals had made her "feel stupid and on the defensive."

Encourage

These parents also pointed out that they need encouragement and reassurance from the professionals much more than they need blame. "I would have welcomed just a little encouragement more than anything else" was one mother's response. Many parents need praise for what they have done well, rather than advice on what they ought to do. As these interviews revealed, the parents have tried many coping strategies and they need to be made aware of their good ideas and the contributions they have made for their child. Professionals could improve their communication with parents if they tried to build their self-confidence and to give them strength to work on the important, sensitive, and difficult job they face.

Advice to Parents

Reach Out

The entire group of parents either directly or indirectly endorsed the value of parent support groups, rather than attempting to go it alone. Informal support was just as important and valuable as formally structured parent groups. The following statements represent the parents' commitment to become involved with others: "Reach out to other parents and don't be embarrassed." and "Get support from parents. One telephone call can lead to a whole network of other parents with similar problems."

Become Informed

Keeping informed about all aspects of a child's disability and parents' legal rights was a second major recommendation. In many instances these parents had become surrogate professionals in order to manage the educational program for their child. In order to meet the demands of this role, they had to be well informed. "You can't look for help until you know what you want, so you have no choice but to get the facts," was one mother's advice to other parents.

Be Assertive

Although the interviewees may not have started out as assertive parents, they certainly learned how to assert themselves when working for the benefit of their children. "Be your kid's advocate and don't give up!" was a common response. One mother laughed while saying, "Be a pleasant pest--in other words, be in constant contact, before, during and after the diagnosis. The squeaky wheel gets the oil, and that's really true." Similar advice was offered by another mother when she said "Don't give up--ever--just remember that if you give up then who do you expect will continue the fight for your child?"

Support Your Child

These parents had a remarkable capacity to stretch their resources, both economically and psychologically, to support their child in ways that would build or repair their child's self-esteem. Four parents, all with mildly handicapped children, recommended that parents try hard to find an activity through which the child can experience success. Skiing, playing musical instruments,

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church work, fun games, scouting, and sports were frequently mentioned. "It doesn't matter what you choose, as long as your child likes it and can feel good about him- or herself." said one mother.

Conclusion

Our involvement with these and other parents of handicapped children has been singularly positive. It has also been humbling. Although the tone of their comments is often critical toward professionals it is important to note that even the most active of parents acknowledged the need for professional leadership. They want to rely on the advice of experts, but not to the point of exclusion. These parents freely admitted that they needed help. The problem was in finding the right kind of help. This is not much different from parents of non-handicapped children. The 1976 Gallup Poll showed that parents of children in public schools were four to one in favor of courses for parents. Parents want to be involved in their child's educational program, and they welcome professional leadership if it is provided in a respectful and democratic manner. A mother said, "You have a powerful voice, please use it."

Parents are very supportive of one another and derive enjoyment and benefit from working and helping others. Without exception the parents appeared to have enjoyed the process of telling us about their experiences and their children. More than one parent said, "I'd do anything if I thought it would help other parents and kids." This commitment reflects only part of the investment--in time, in energy, in worry, in effort--that every parent, even the most casual, pours into a child. Parents want to hear the professionals. If we, as

professionals, want parents to listen to us, we must somehow learn how to say what we want to say in the way they will want to listen. Parents of handicapped children do not belong to a homogeneous group. Each parent deserves to be known and understood for himself and herself. Only by learning to know each parent well is it possible to develop an individual interaction program.

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The Advocacy Process

William L. Dussault

ad-vo-ca-cy, n. act of pleading for, supporting, or recommending; active espousal.

The other chapters in this monograph describe the continuous struggle to establish enforceable legislative rights for education for disabled children. The decade of the 1970s provided a long line of judicial decisions affirming the rights of handicapped children to education in all 50 states of the United States. The passage of the Education For All Handicapped Children Act was a landmark recognition of philosophical commitment to the concept that all children have a right to an appropriate educational opportunity. Countless hours of time and deep personal commitment by a small number of dedicated parents and professionals were

required to force legislation that recognized the right of handicapped children to appropriate education.

Once PL 94-142 became a reality, many of the initial activists sat back to congratulate themselves on their victory. Levels of commitment dropped as the compliments on work well done and the feeling of satisfaction expanded across the national scene for all of those who had worked so hard. But the question must now be asked, was the job finished or the opening stanza barely completed? It should be evident now, even though only a brief amount of time has passed since the effective date of the implementation of the law, that the major challenges of implementing the new law still lie ahead.

A Great Deal of Work Remains

In the Second Annual Report to Congress on the Implementation of Public Law 94-142 (U.S. Department of Education, 1980), it is reported that there is increasing evidence that significant numbers of unserved handicapped children are in regular classrooms in the nation's 16,000 school districts. Many children remain on waiting lists for both screening and placement. According to the report, individual states are serving only 2.6% of their total school population between the ages of three and five. On the average, states are serving only .73% of their school population in the age group 18 through 21.

At the time PL 94-142 was being discussed in Congress, it was widely speculated that approximately 12% of the total school population would qualify for services under the law. Through school year 1979-1980, however, the states and territories

averaged only 9.54% of their total K-12 population in special education, with nine states serving less than 8% of their school age population in special education. The District of Columbia served only 4.91% of its population in special education. The discrepancy between the projected numbers of qualified recipients of special education and those actually receiving services is alarmingly high.

In addition to the problem of under-served or un-served children, the Report to Congress notes that,

In general, IEPs need particular improvement in specifying the extent of participation in regular education programs and providing proposed evaluation criteria for determining the extent to which short term objectives are being achieved...Many issues have surfaced concerning the provision of related services and the fact that certain services, such as physical education and vocational/prevocational education, are infrequently specified. (p. 7)

These problems are, in part, due to the lack of available resources. Large numbers of teachers and support staff are needed to provide appropriate services to individual children. But there can be no excuses for lack of parent involvement, especially in the development of an IEP. The GAO report indicated that, based on teacher reports, only 49% of the parents of public school handicapped children actually served as a part of the IEP Committee and provided information contributing to IEP development. In general, parents are relegated to the position of approving programs formulated by the district, rather than participating actively in the formulation of the program. The author's experience, when working directly with parents in many states, indicates that two additional and significant problems continue to impede the full implementation of an IEP for each child.

First, it would appear that a vast number of school districts still evaluate children only for the purpose of categorizing them into a particular disability subgroup. Often, this procedure occurs because school districts receive state funding based upon the number of children in a particular category and not upon the service needs of the individual children. The result of evaluation for categorization only is that children's individual needs often become submerged and secondary to their perceived categorical needs. The second problem is closely tied to the first. When children are categorized, placement is often based upon the label the child bears and not upon individual needs. Children are placed in programs that have been available traditionally. The design of new and innovative programs to meet unique needs is not occurring on a widespread basis for many children. Special education is still perceived as being provided only in the "special education room," and mainstreaming is again becoming synonymous with dumping. District personnel do not understand that the so-called "regular" program teacher, with some assistance and training, can provide appropriate, specially designed instruction, just as can the "special education" teacher.

While criticism of the law, its regulations, and their implementation have been widespread, this author remains firmly convinced of the law's basic strength and inherent value. A radical, perhaps even revolutionary, new approach to education has been established. It would be tragically naive to assume that the course of implementation would be smooth or rapid. No law is self-enforcing or self-regulating. Certainly, the Education For All Children Act is not an exception. Notwithstanding its alleged shortcomings, it provides us with a procedural mechanism to resolve problems in a way that can guarantee effective and appropriate individualized education for each handicapped student. The author

remains firmly convinced that, armed with a reasonable understanding of the basic concepts of the law, the self-confidence that comes from knowledge, the commitment and dedication already required to be the parent of the handicapped child, and competent assistance at critical stages, every parent can be a successful advocate for his or her own child's program.

The Process of Advocacy

In a sense, the title "The Advocacy Process" is too broad for this paper. Advocacy has become a fad or current word, almost a cliché. It includes, but is not limited to, the following:

1. Legal advocacy, with the use of lawyers, courts, due process, and attendant complications;
2. Citizen advocacy, either done individually on behalf of one person, or by lay advocates who may be paid or unpaid through national or local organizations;
3. Case management advocacy, with government agencies providing the service;
4. Systems advocacy, directed at broad change for large groups of persons across whole service delivery systems;
5. Legislative or political advocacy, including formal or informal lobbying and public relations.

Obviously, this monograph could be used as a tool within many of these categories of advocacy.

Furthermore, the advocate role can be played by either parent or professional. It should be clear from the outset, however, that not all aspects of the advocacy process will be covered in this paper. Rather, the purpose of the paper is to direct our attention to the parents of a disabled child who are having some difficulty in obtaining what they believe to be an appropriate educational opportunity for their child. The interaction between the parents, as advocate, the school district, and the law thus becomes the focus.

A Warning to Future Advocates

Any individual determined to become an advocate should be forewarned. There are some persons who perceive advocates only as mean, troublesome, meddlesome persons. Wolf Wolfensberger has said that when advocacy begins to work, it will be persecuted because it will be a threat. Conversely, the phonier an advocacy system is, the more likely it is to be praised, legitimized, exulted and funded (Note 1).

The advocate's lot can be a difficult one. By advocating for others, one's own children could suffer retaliation. By advocating for one's own child, community pressure, and even ostracism could occur. The advocate becomes the trouble maker, the one who is "outside" throwing stones at the system, causing expenditure of assets on hearings and lawyers, rather than on programs.

Many individuals who have been effective advocates have certainly been so castigated. It needn't be thus, however. It is possible to be an advocate without being an "enemy." Not every special education "problem" degenerates into a situation requiring a Due Process hearing. Many advocates who are successful in presenting their cases are able to do

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so without either being co-opted by the system or becoming an enemy of the system. Some basic principles might be suggested here that can be generalized to any "advocacy" situation.

1. Most important, in any situation in which you choose to be an advocate, know what you want.
2. Always do sufficient preliminary research to know the limits of authority of the person to whom you are presenting your case. Present your case to an individual with sufficient authority to make and implement a decision in your favor.
3. Prepare your "case" completely, keeping in mind at all times your ultimate goal.
4. Present your case firmly, fully, and respectfully, not abusively or angrily.

This author has been involved in more than 100 special education problem situations over the past five years. While some situations have required Due Process hearings and a few have required appeals to the State Education Agency with subsequent State and Federal Court Appeals, the majority of cases have been handled without resort to formal Due Process hearings. Most have been resolved through compromise between the parties, with the parents and student (if of sufficient age) always having approval authority over the ultimate terms. A review of the processes used by our office may be illustrative in assisting persons both in being their own advocates and knowing when additional outside advocacy is necessary.

A Problem Exists

Frequently, by the time parents come to an attorney for assistance, a significant special education problem is already evident. The relationship between the parents and the district may have broken down completely. Conflicts in personality may have taken precedence over the primary issue of the appropriateness of the educational program, the need for related services, the need for a more complete evaluation, and so on. The parents and the district are at odds, with both sides being anxious to "win" at any price. Unfortunately, often the price to be paid is more than just the cost to the parents for attorney's fees and the cost to the district for the hearing examiner. The real cost to be paid is the loss or delay of appropriate educational programming for the child while the competing parties battle, waving the banner of Vince Lombardi's slogan that, "Winning isn't everything, it's the only thing."

Such a situation need not occur. Several steps can be taken by both the parents and the district to avoid the frustrating, time-consuming, and expensive involvement of outsiders in what should be an open, honest, and equal give-and-take relationship between the parent-professional and the educator-professional.

Sharing Information

School districts should ensure that all parents of handicapped children in their purview are advised of their basic rights under the law, in language that is understandable to them. Moreover, the rights should be verbally explained in a meaningful way, rather than by a mimeographed page of "fine print" with no discussion whatsoever with the parents. Many states have now drafted parent information handbooks written in easily understandable language, sometimes in question and answer form, which explain options

available to them under the law. In providing this information to parents, and explaining it simply, the school district gains several important advantages.

First, it establishes an atmosphere of cooperation and trust, by disclosing information that the parents have a right to know. If the parents are forced to locate this information from an outside source, the school district has suffered a drastic loss in credibility from the outset.

Second, by providing a simple and understandable explanation of the laws, the school district will not only educate the parents, but it will educate its own employees, thus lessening confusion and minimizing the chances that its employees will inadvertently be party to activities that will place the district in conflict with the regulations.

Finally, the district sets easily understandable ground rules by which both parties can "play" the game.

In the event that the district does not provide basic information on rights to parents, the parents will have to obtain it another way. Several options are available. The state education agency should have copies of both the federal and state special education laws and regulations available for distribution upon request. Parents should request any state-agency-sponsored bulletins or pamphlets describing special education and the law. Copies of the federal regulations may also be obtained from the local offices of the U.S. Department of Education or the offices of Congresspersons or Senators. A copy of the state's current plan for providing special education in compliance with the federal laws could also provide valuable information. The plan is a public document and is obtainable either from the state education office or from the Special Education Programs (formerly Office of Special Education) of the U.S. Education Department.

Gather a Support Base

Long before the parents are placed in the situation of needing to be advocates on a problem-by-problem basis, it would be wise for them to become members of one of the many community organizations established on behalf of handicapped persons. Such organizations might include The Association for Retarded Citizens, United Cerebral Palsy, Society for Autistic Children, Organizations for the Orthopedically Impaired, Neurologically Impaired, Behaviorally Impaired, Council for Exceptional Children, and many others.

The costs of such memberships are usually minimal. Many of the organizations provide memberships even without the requirement for payment of dues. Valuable information is disseminated through monthly meetings and newsletters. Political trends, budget advice, program ideas, and information about new options and alternatives available are often discussed. The other parents involved can provide help and support for one another and, in doing so, form a necessary grassroots force to effect the overall system change that is often necessary.

But perhaps the most important reason for such an association, when one is faced with a problem that may require advocacy, is the availability of information from other members in the group concerning the basic attitudes of the school district involved. An understanding of the basic philosophy and attitudes of the people providing the program in the school district is absolutely essential to the proper preparation and presentation of an advocacy position. If one is able to determine that the Special Education Director is strongly committed to the provision of quality and appropriate special education programs and has the power to implement such programs, it can be reasonably assured that a positive, straightforward, well-prepared approach has a reasonable chance at success. If, on the other

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hand, one is dealing with a school district in which the Special Education Director has no authority, or equally important, has no commitment to appropriate programming, the approach must be totally different. The presentation will then need to emphasize compliance with regulations and strict adherence to timelines. A cooperative effort toward resolution is less likely. Full written documentation of all procedural steps must be obtained, including written confirmation of subjects discussed and recommendations made or received in any personal conferences or telephone conversations. Recourse to experienced advocates and attorneys may be necessary in order to force unwilling compliance from the district, and equally important, to monitor program implementation for continued compliance. A competent independent educational expert is invaluable in such situations.

It is critical to know whether or not the district is failing to provide programs because of a perceived lack of financial resources, because of lack of appropriately qualified staff, because of philosophical disagreement with a particular proposed program, or simply because of the obstinance of a director on a personal ego trip who believes that educators are always right and parents are always wrong. Other parents who belong to the organizations described previously may have had difficulties with the same district in the past. They can provide valuable insights into the attitudes and personalities involved. In attempting to discover reasons other than those that might originate in personality concerns, it might be well to simply ask someone in the district, What are the problems you have in giving my child a fully appropriate program? If the question is asked in an open and honest way to a person who has provided good information to parents in the past, it is likely the parents will again obtain a straight answer. While this information should not necessarily change the goal, it may

radically change the type of approach one will have to make to the district. Many of the district's problems, although real and pressing, do not justify a denial of appropriate programs for all handicapped students.

When Should Advocacy Start?

Educational advocacy should commence long before a conflict or problem arises between the parents and the school district. One of the most important qualities of the competent advocate is preparation. Preparation should start prior to the IEP Conference and, quite probably, prior even to the evaluation of the child. From the time the child is enrolled in school, parents should maintain a complete copy of the student's school records. Active involvement through parent conferences should take place on an ongoing basis.

✓ Children with severe disabilities have obvious needs for assistance. Advocacy for their programs should start at birth. Children with mild difficulties are often "not classified" as handicapped for purposes of the law until later in their educational programs. A collection of papers they have completed, art projects they have done, report cards they have received, tests they have attempted, and other school records can be valuable in documenting the need for special programs. If the parents have failed to maintain such a record, the school district is obligated to provide copies of the school records upon reasonable request by the parents. While the school district is obligated to provide any information in the school records to the parents, they may charge a reasonable copying expense for providing the documents.

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What Tests Can I Trust?

When a child is referred for special education evaluation, the district is required to comply with certain evaluation procedures. Any tests or evaluation materials must be provided and administered in the child's native language, or through another, appropriate mode of communication. It is important to remember that many of the so-called "standardized" IQ tests have not been validated for use with handicapped children. They are particularly subject to question when used with children with either perceptual deficits or physical disabilities, especially if the tests require timed answers or answers completed only with pencil and paper. Any tests given must have been validated for the specific purpose and population for which they are used. Thus, if a vocational evaluation is being given, tests validated to predict vocational ability or outcome should be used. Likewise, evaluation materials must be tailored to assess the specific areas of educational need.

A particular note of caution to parents of learning disabled and/or hearing impaired children--be sure to scrutinize closely tests that stress verbal performance. The perceptual difficulties of these children make them particularly susceptible to unduly deflated scores in these areas. We are also noting with increasing frequency the importance of complete neurological evaluations, including psychoneurological testing, as the incidence of undiagnosed and previously unsuspected neurological dysfunction and seizure disorders seems to be increasing.

Tests that result in a single IQ score may also be used for placement purposes, but have little diagnostic value unless coupled with additional tests that review actual needs. No single procedure should be used as the sole criterion for determining the

appropriate educational program for the child. Reliance on averaged scores, rather than close scrutiny of sub-test areas by qualified professionals often leaves a district with a highly inaccurate picture of the child's ability.

What Does the Multidisciplinary Team Do?

The district is required to evaluate the child through the efforts of a multidisciplinary team or a group of persons, including at least one teacher or other specialist with knowledge in the area of the suspected disability. All of the areas of suspected disabilities should be evaluated, including, where appropriate, health and vision screening, social and emotional status, general intelligence, academic performance, communicative status, motor abilities, and even complete medical and neurological evaluations. The district may utilize outside evaluations previously done, or may even request new evaluations at its own expense when indicated. Both the parent and the district must realize that the purpose of the evaluation isn't simply to qualify the student for special education, so that the student generates money for the district, but rather to determine the actual functional ability and disability of the student and to provide a prescriptive program based upon those factors. If the only purpose of the evaluation is to generate a general category or qualification for state funding purposes, and sufficient information is not provided to allow for competent individualized planning for the student, then the evaluation is inappropriate and inadequate. The program must flow from and be directly related to the evaluation.

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What Classification is Appropriate?

Many parents and advocates are still being sidetracked into arguments as to which classification is appropriate for the particular student. A district may classify a student as mentally retarded when the parents believe the student is more appropriately classified as learning disabled. These arguments often occur in states where local school districts generate state and federal dollars for children based upon the number of children in particular categories. The author would suggest that this issue is a red herring. The issue of category is one that is properly argued only between the local education agency and the state. The key issue between the parents and the school district relates to the appropriateness of the program proposed for the student, not the funding label the student bears. Unfortunately, many school districts around the country still determine educational placements or student-teacher ratios based upon the classification of the child. In this respect, an argument about classification may seem pertinent, but it must be remembered that the key legal argument is one that relates principally to the appropriateness of the child's IEP to his or her unique needs. One could facetiously say that, insofar as the parents are concerned, any label could be used as long as the program provided to the child is appropriate to his individually demonstrated needs. Obviously, a competent evaluation clearly defining those needs is critical to the design of the ultimate appropriate program.

When to Use an Outside Independent Educational Evaluation

The federal regulations provide that a parent may request the district to pay for an Outside Independent Educational Evaluation in the event that

the parents do not think that the district's evaluation is appropriate. In order to determine whether or not an outside evaluation should be requested, the parents should obtain copies of all test summaries and test results completed in the district's evaluation. The parents should review those test results, and if there are any questions, either about the kind of test given, the test results, qualification of the person giving the test, or the applicability of the test to the particular child's disability, the parents should request a conference with the school district personnel responsible for giving the tests. In such a conference, the parents should be especially concerned about ensuring that the tests given bear a direct relationship to the child's particular disability. The parents should insist on an explanation from the school district personnel in language that is understandable to the parent, free from psychological jargon. If the parents are left with the instinctive feeling that the tests are not appropriate to the student, or that the results do not accurately reflect the student's capacity or needs, then the parents should either request additional tests from the district or should seriously consider requesting outside assistance.

In the vast majority of cases, parents will not be aware of the specific tests given, how the tests are applied, and what the tests are intended to measure. The yardstick for the parents in measuring the appropriateness of the tests is how well the tests describe what the student can and cannot actually do. The parents have a wealth of experience in their ongoing relationship with the child in making an evaluation of the evaluations. If questions persist after in-district explanations are received, it would be well to seek the assistance of an advocate who has had prior experience.

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If it is decided that an outside evaluation is necessary, then the parents should have the freedom to choose who will do the evaluation. While recommendations from the school district should be considered, so should all recommendations from the advocacy agencies with which the parents are involved. The outside evaluation should consist of all appropriate tests necessary to assess the child's abilities properly. An important component of the final report of the outside evaluation should be the specific recommendations made concerning program design for the child.

The parents might also keep in mind, when choosing a facility for an outside evaluation, that it might well become necessary for a representative of that outside facility to provide testimony as to the appropriateness of both the district evaluation and the outside evaluation. The district does have the option, under the federal regulations, of requesting a hearing for the purpose of demonstrating that its in-house evaluation is appropriate. Should this hearing be called, the outside facility will no doubt be required to provide testimony to support its own viewpoint.

Even if the parents choose to obtain an outside evaluation without requesting the school district to pay for it, the school district must still consider the results of that assessment in preparing the IEP. Because the outside independent facilities are not generally tied to a state funding system that rewards placement of a child in a particular category, outside assessments are often more helpful in providing prescriptions directly related to the child's individual program needs.

In the event that a school district does choose to request a hearing to place the cost of the Outside Independent Evaluation upon the parents, it may be a good idea to suggest delaying that hearing until both

the school district's and the outside assessment can be compared. Additionally, once the outside assessment is received, discussions concerning the program can commence immediately. If there is to be an argument over the program as well as payment of assessment, it can be accomplished in one hearing, thus minimizing cost and time involved. The alternative is to have a Due Process hearing to discuss the issue of payment for the outside evaluation, complete that hearing, obtain the outside evaluation, and then have a second hearing to discuss program elements. Obviously, the cost and delay would be substantial in the latter situations. It is far more reasonable to determine whether or not there will be an argument over program elements before establishing who will take the economic responsibility for the outside evaluation. If there is no argument over program elements, it may be worthwhile to compromise the issue of payment on the outside evaluation in order to continue cooperative relationships between the district and the parents.

The IEP Conference

The single most important contact between the school district and the parents occurs at the IEP Conference. Generally it is the school district's prerogative to schedule this conference. The regulations do provide that the conference should be scheduled at a time that is mutually agreeable to the parents and the school district. The convenience of both parties must be considered in choosing that time. Both the school district and the parents should be fully prepared for the conference. The school district's preparation may seem obvious. The district should have completed an evaluation of the child which considers the child's actual day-to-day program needs. Based upon the child's evaluation, the school district should have suggestions available, both as to the nature of the specially

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designed instruction that the child is to receive, and all related services needed by the child. The district must remember that it has an obligation to provide programs for the child on an individually designed basis and not solely upon the programs the school district has presently available. The district should be prepared to discuss its program proposals and placement recommendations completely, knowing they are fully subject to amendment or rejection by the parents, the other equal partners in the IEP Conference.

The parents should prepare for the IEP Conference by thoughtfully reviewing all of the student's prior educational records. The parents should consider what has worked or failed in the past for the child. The parents might prepare a one-page summary of the child's behaviors when not in the school environment. How does the child respond to distraction? Does he or she follow one- or two-step directions, or can more complicated directions be given? Are there particular things that the child will respond to well which can be used as a reward for good behavior? Does the child respond well to verbal praise? Is the physical reinforcement of a hug necessary? Will a gold star on a paper be meaningful? It is possible that even more basic rewards are required, such as food.

The parents need not have a precise idea of what specific teaching program should be applied to meet the child's particular individual disabilities, but the parents should keep well in mind what the general focus of education is for the child. It is this author's prejudice that special education for handicapped children should serve one primary purpose above all others: the development of sufficient independent living skills that, at the end of the child's educational career, the child will have moved towards living independently as a self-supporting

member of the community. While total independence might not be an appropriate goal for every child, independence to the maximum of potential should be.

It is possible that the parents may feel intimidated in the IEP Conference. This is often the case, particularly when school districts load their side of the table with two, three, four, or even more professionals who speak in a language that is totally unfamiliar to the parents. The best way to overcome that kind of intimidation is to ground the subject of the conference firmly in the particular child to be addressed. Each time a professional statement is made, it should be directly related to and explained in the context of the child involved. The parents should feel free to ask such questions as, How does that apply to my child? and How will that work in the classroom on a day-to-day basis? or How will that move my child toward independence? If the parents do feel intimidated in an IEP conference, a final proposed IEP probably should not be signed at that time. The parents should request a copy and take it home to study in a less pressurized environment. At that point, the parents may contact other parents who have worked with the program or an outside advocate to ensure understanding of the district's proposed program components.

The federal regulations provide that the IEP should contain objective criteria, evaluation procedures, and schedules to determine whether the short-term instructional objectives established in the IEP are being met. This requires that the objectives be established in language that allows for measurement of the child's progress over time. The IEP is not a contract that guarantees that progress will be made in the child's program; however, it is the basic planning tool for evaluating whether the program is or is not successful. If progress under the IEP is evaluated only on an annual basis, much time could be lost if the child is not able to benefit from the

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program designed in the IEP. The lack of the child's progress may not be the school district's "fault." It may simply mean that the program chosen is not the appropriate one for the child. The important factor here is not that the school district admit fault or legal responsibility for the lack of progress, but rather that the program be changed as quickly as possible to become appropriate for the student. Thus, provision for monitoring student's progress within the program at short intervals (even biweekly) is critical. It should be requested by the parent, and should be specifically included in the IEP. The goal must be to keep the IEP relevant to the child's needs.

Many parents become extremely concerned about the actual physical location of the program. It is generally not as important that a particular special education program be offered in a particular building or classroom, as long as the program offered is appropriate to the individual student. Extended transportation time, inappropriate physical facilities, physical facilities that don't allow for therapies or other necessary related services may all be exceptions to the general rule that program location is not as important as program content. These should be explicitly considered in completing the IEP.

If the discussion in the IEP Conference has been open and cooperative, the district has made suggestions for the child's program that appear directly related to his or her needs, and the child's progress towards the goals and objectives can be measured in an objective way, the parent may wish to sign the IEP immediately and commence the program as quickly as possible. On the other hand, the parents certainly have a right to take a copy of the district's proposal home and consider it, obtaining whatever outside assistance is appropriate.

IEP Follow-Up

The advocate's job is not completed when the IEP is signed and the program commenced. Progress toward the short-term objectives and the annual goals should be monitored. Ongoing contact with the special education teacher, any therapists, and any regular program teachers involved in a mainstreaming program is critical. The short-term objectives in the IEP should not be cast in concrete and both sides should be amenable to change based upon the child's experience and progress in the program. The parents should expect, and the school district should provide, training for the parents and at-home programs that will further the child's school program. It should be evident to all parties involved that the program for the child must be consistently applied, both at school and at home, in order to be effective. If the two areas of the child's life are working at cross purposes, confusion will result and progress may be extremely limited.

The parents are faced with a much more difficult situation when it is felt that the school district is not being responsive to the child's needs or that the appropriate program for the child is simply not being made available. If the parents have the feeling, either at the IEP conference or immediately thereafter, that the district is not willing to provide an appropriate program for their child, then the parents should take several preliminary steps before deciding to make a Due Process appeal.

Decisions Regarding a Due Process Appeal

First, the parents must review the child's educational goals in light of the school district's evaluation material. The parents must decide if the

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goals can be realistically established. The parents need to evaluate whether their position is essential to an appropriate program for the child and is not about a false issue, such as categorization or dollars available. They must also attempt to identify the areas of disagreement with the school district and determine in each area of disagreement the specific desires for the child's program. If the parents are not able to say what is necessary to provide an appropriate program for the child in that area, then it may be necessary to seek outside assistance. In attempting to clarify the problem areas, it might be well to talk with the direct staff who have been working with the child. Last year's teacher, therapist, or classroom aide may be able to provide information that will assist in clarifying this year's program needs.

If a conflict does exist between the parents and the district on a program element important to an appropriate education, several alternative methods of approaching the district are possible. If one is dealing with a cooperative district and is involved in a good faith disagreement as to a program component, it may be best to use an outside professional for an independent opinion. All parties should welcome such an opportunity to avoid the potential for a hearing. It might be extremely advantageous to the parents and child to suggest that they and their expert meet the district representatives in an attempt to resolve conflicts before they resort to Due Process. Careful scrutiny of the district is required in this situation to ensure that the district truly does have a good faith program disagreement and is not simply stalling to gain time.

If the parents believe the district is not acting in good faith, it would be well to file a Due Process request immediately in writing. Further, with such a district, this author would strongly urge the

services of an outside advocate, and probably legal counsel, in preparing and presenting the case to that district. Every conversation with such a district should be confirmed in writing. A carbon copy of each communication should be kept, with an indication as to whether the letter was mailed or hand delivered and the date of mailing or delivery in each case. Continued emphasis in the letters on the hearing timelines should be maintained. During the pending of a Due Process hearing where procedural and program issues are to be argued, extensive notes should document any harm to the child as a result of the district's procedural violations. As a general rule of law, in the absence of direct harm to the student, little relief will be granted to the parents who wish to argue only issues of compliance with procedures or timelines.

It must be emphasized that any Due Process hearing may be unpleasant, adversary in nature, and quite likely technical. This situation is more likely to occur when the district does not really have a good faith type of disagreement with the parent. Legal representation should be considered in order to properly preserve the parents' position for a future court hearing.

Preparation for a Due Process Hearing

In preparing for a Due Process hearing, the parents, individually or under the direction of an attorney, should be sure to marshal all evidence and witnesses and come fully prepared to the hearing to focus on the program issues necessary to provide an appropriate educational opportunity for the child. The child's program needs must be the focus of the hearing. Whenever possible, witnesses should be available in person to give testimony. Names, addresses, and professional qualifications of witnesses, together with a list of any documentary

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evidence, should be exchanged with the district not later than five days before the hearing. The school's student records should be reviewed prior to that time to ensure that no surprise entries have been made pending the hearing.

The testimony of the witnesses for the child should always focus on the appropriate program for the child. The child's individual needs should be kept foremost before the hearing examiner. As the hearing examiner will be making the primary decision in the case, the personality and qualifications of the hearing examiner becomes an additional aspect of preparation that cannot be overlooked. The rules require that the district provide parents with a list of the names of potential hearing examiners, together with their qualifications. This list should be reviewed by the parents and discussed with other advocates who may have had experiences with the various recommended hearing examiners. Copies of prior decisions made by the various hearing examiners can often be obtained from the state education agency. While a hearing examiner may not have decided a case exactly like the one immediately at hand, prior decisions may give valuable insights into attitudes and prejudices. The hearing examiner should have no prior employment (other than hearing officer) or interest in the district. If a parent has any question concerning the expertise or background of a hearing examiner, that question should immediately be expressed on the record at the hearing, firmly, but respectfully.

Pre-Hearing Conference

There has been a great deal of discussion, both at the local and national levels, toward requiring a "pre-hearing conference" between the district and the parent prior to moving ahead with the formal Due Process procedure. As I have indicated, if the

parents are dealing with a school district that the parents perceive is responding in good faith, then the parents should have taken all steps to exhaust the possibility of a compromise before requesting a Due Process hearing. Thus, a pre-hearing conference or settlement conference would have little chance of a positive result. In some circumstances, however, the intervention of a formal hearing examiner, encouraging a pre-hearing settlement, can often be beneficial.

If the parents, on the other hand, are dealing with a district that is perceived as acting in bad faith, then a pre-hearing conference or settlement discussion will have little impact other than delaying the inevitable. In neither circumstance, whether good faith or bad, once the request for hearing has been made, should the 45-day hearing timeline be waived for the purpose of a settlement unless there is an extremely good likelihood that a settlement will occur. It is unlikely such a situation will arise if both parties have made good faith effort to reach an agreement on the child's program prior to instituting the hearing procedure.

Levels of Appeal

Even if the parents proceed to a Due Process hearing and are successful, several levels of appeal may still follow. While these appeals are pending, the rules provide that the student should remain in the program provided at the time the hearing was requested, unless the parents and the district agree otherwise. Discussion regarding interim placement must be considered, especially when the hearing is being called to discuss initial placement. While both parties can "agree to disagree" as to ultimate placement, in many instances an absent agreement on an interim placement may mean the child may be denied all educational programming. A less-than-ultimately appropriate program should be explored to avoid total denial.

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Both the school district and the parent should be aware of when to quit. Many hearings and subsequent appeals are taken far beyond the point at which appropriate programming for the child is the issue. One or both parties may become more interested in teaching the other side a lesson or setting a general precedent. These goals become perceived as more important than the individual program needs of the child, who is the focus of the hearing. There is no shame or disgrace in saying, That's enough, this has gone too far, let's again try to focus on the individual needs of this particular child. While it is important to try and set precedent so that other children will not have to fight the same battles, it must be remembered that the critical issue is the appropriateness of the program for the child.

Parents should be aware that there are additional options available to them when they are dealing with a school district that is responding in bad faith. Protective systems have been established in addition to the Due Process procedures of PL 94-142. Both state and federal antidiscrimination laws specifically pertain to education. Section 504 of the 1973 Vocational-Rehabilitation Act, as amended, prohibits discrimination on the basis of handicap in any program receiving federal funds. This clearly includes all school districts. Many state antidiscrimination laws have been similarly amended to prohibit discrimination on the basis of handicap. Education may be one of the programs to which such state discrimination laws apply. Under both state and federal antidiscrimination laws, additional administrative complaint procedures may be available. Such options include complaints through the Office of Civil Rights of the Department of Education or complaints through state human rights agencies. Recourse to such agencies are called Administrative Remedies.

Parents might also have the right to bring private lawsuits against school districts that discriminate against handicapped children. Lawsuits may be brought either under Section 504, referred to previously or under specific state discrimination laws. Monetary damages and payment of attorney's fees have been awarded, under both state and federal laws, against school districts that discriminate against handicapped students.

Other forms of advocacy might involve the making of a Citizen's Complaint to state education agencies about the continued patterns of violations present in the local school district. Under the rules and regulations of PL 94-142, the state educational agency is required to investigate and take action on citizen complaints. If there is a pattern of violations, federal funds and, in some states, state funds, may be withheld to ensure compliance.

Additional forms of advocacy against a recalcitrant district might include disclosures to the press, and discussions with local county or state political representatives. Few school districts wish to have their local senator asking embarrassing questions about an individual program when the school district has to return to that state senator to encourage state funding of education at a later time. Whenever parents take recourse to such outside advocacy processes, they should ensure that any claims made are well documented and are based on the truth.

Summary

It is indeed unfortunate that the term advocacy has, in many areas, become synonymous with the term "adversary." The competent advocate has many options at his or her command. Well-prepared parents, with

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specific program goals clearly in mind, should not have to resort to a complicated and expensive legal procedure. The art of compromise and negotiation should be fully explored whenever there is a reasonable chance to believe that the child's program needs can be met. Once it becomes obvious, however, that a district is not willing to negotiate or discuss further the individual child's need for an appropriate program, then the parent/advocate is left with little option but to force involvement in the adversary procedural system.

This author's final comment would simply be that a good advocate should avoid Due Process except as a last possible resort. But once that resort becomes necessary, then the advocate must be prepared to fight and win at all costs. For what is at stake is not merely the provision of one simple service on a one-time basis, such as the provision of physical therapy or the application of a particular teaching methodology to the student; what is at stake is the child's entire future, and in certain circumstances, maybe even the child's life. The consequences of an inappropriate or incompetent education are so severe as to be immeasurable. If the advocate is not prepared to accept the seriousness of that challenge, then he or she is not prepared to be an advocate.

Reference List

U.S. Department of Education. Second Annual Report to Congress, 1980.

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Reference Note

1. Wolfensberger, W. Speech presented to President's Commission on Mental Retardation: Century of Decision.

An Integrative Model of Parent Involvement

Judith Sewell Wright

Parent involvement in the education of the handicapped child has become an important aspect of the child's education. Historically, professionals and service providers have been child or client focused. The professionals involved in special education and allied disciplines have been trained in child development with a focus on the child's handicap. Professional responsibility to parents has traditionally been only to inform them of their child's progress. Now, however, parent participation in the education of the child is a reality. Several factors have contributed to this change.

Political pressure by parents of handicapped children has contributed to increased parent participation in the education and training of these children. Additionally, it was discovered that

nonprofessionals could act as powerful change agents. The positive results of using paraprofessionals or nonprofessionals for providing therapeutic or educational services (Guerney, 1969; Tharp & Wetzel, 1969) lent credence to the concept of training or using parents as change agents for their children. Another factor contributing to parent involvement has been the success of special education and therapy techniques. Clinicians reasoned that if the therapeutic effects of one day of intervention were beneficial, then progress could be improved if intervention were carried over into the home environment throughout the week.

Recent research has shown that parent involvement in early education programs has constructive impact on the child's development (Bronfenbrenner, 1974). Indeed, parent involvement in early intervention has been shown to be necessary for maximum developmental progress (Bricker & Bricker, 1976; Fraiberg, 1975; Horton, 1976; Shearer & Shearer, 1976).

Thus, parent involvement has been recognized as a necessary and beneficial component in current early childhood education. Because of the mandate of PL 94-142, parent participation is no longer a luxury, but a necessity. The question is not whether to involve parents, but how.

There have been three main approaches utilized in parent involvement. Two of these major approaches serving or involving parents in the therapeutic process with their children have been identified by Tymchuk (1975): by training parents to be teachers of their handicapped children, and by providing counseling for parents to help with their acceptance of their child. A third approach has been to provide programming to enhance mother-child interaction (Bromwich, 1976; Kogan, Gordon, & Wimberger, 1972; Mash & Terdal, 1973; Seitz & Terdal, 1972). These three forms of parent

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involvement have advantages and disadvantages which are reviewed in the following sections. The question arose as to what could be done to benefit from the strengths of each of these three methods.

To explore this question, research findings and experiences in the field will be traced in order to develop a model of parent involvement. This model is currently used in the Early Childhood Intervention Program at the Institute for the Study of Developmental Disabilities at the University of Illinois at Chicago Circle. Although the model has been developed for use with infants and young children, many of the concepts also apply to handicapped children of all ages and their parents.

Training Parents to Train Their Children

Professionals began training parents to train their children in order to maximize the effects of therapy and special education. In essence, parents were trained to be educators and/or therapists with their children. Many training programs have documented their effectiveness in maximizing the handicapped child's developmental progress through parent teaching. Programs have been successful in teaching parents to modify the behavior of their children (Frazier & Schneider, 1975; Fredricks, Baldwin, & Grove, 1976; Hayden, 1976; Watson & Bassinger, 1974). Programs in which parents were trained to train their children have also been successful in facilitating the children's self-help skills and language development (Fredricks, et al., 1976; Watson & Bassinger, 1974). Parents have also been successful in becoming educational therapists for their children, improving their children's functioning in the major areas of development (Freeman & Thompson, 1973). Obviously parent

programs vary in the level of sophistication and formality of the training; however, the major focus is usually on instructing the parent to become a teacher and/or therapist with his or her child.

Training parents to train their handicapped children is now common practice, and takes many forms. Some programs invite parents to observe classroom activities on a scheduled or an informal basis. Parents are encouraged to observe the teacher or therapist working with their child and to generalize the activities to the home situation. Other programs embark on more formal and systematic training sessions, in which parents are instructed in how to train their children. Often these programs include training modules. Some of the common strategies include demonstration, video tape, and didactic presentations. Parents are then asked to demonstrate mastery of the task with their child as professionals observe them, sometimes through video tape or one-way mirrors. Some parent programs work with only the parents involved, and not the children. In these, group meetings are held to provide orientation, demonstrations of techniques, and take-home materials. Subsequent meetings are held for parents to raise questions and receive guidance (Levitt & Cohen, 1976).

An additional part of training parents to teach and/or perform therapy with their child sometimes includes instruction in data collection (Fredricks, et al., 1976; Shearer, 1976). Parents are instructed to collect behavioral data. After a baseline is established, they are asked to make an intervention with the instructed technique. By keeping an ongoing data base, they are able to evaluate their child's progress before, during, and after intervention. Often parents are asked to collect data on their own performance as well as on that of their children.

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Beyond training parents to implement particular treatment skills, many programs involve teaching parents the underlying principles and theories of education and therapy. Parents are instructed in Piagetian concepts of development, principles of neurodevelopmental treatment, and/or behavioral management. The assumption is that if parents understand the theories, they can develop their own strategies and techniques to use with their handicapped child. It is hoped that this knowledge will generalize across settings and developmental stages.

The effects of these programs are varied. For those parents who incorporated the program activities into their lives, their children made gains, and for those who did not, the children did not. As a result professionals became frustrated when parents did not implement what they were taught, and it was tempting to label them as apathetic, unconcerned, or uncooperative. The more determined professionals designed behavior modification programs for the parents in hopes of enlisting their cooperation. Additional parental incentives, such as providing transportation, paying for babysitters, or calling parents in advance of meetings, were also used to improve parent involvement. Some programs even paid parents to attend the sessions, or required parent involvement before serving the child. Others asked parents to serve as aides or volunteers in the program. More than one creative professional has offered to take parents out for a drink if they attended the program.

The benefits of training parents to train their children are well known, but some drawbacks exist. Few parents have the time, knowledge, or energy to develop and implement sophisticated programs for their children. Even if they demonstrate mastery of a skill in the classroom, that skill may not necessarily generalize to the home setting, for any number of reasons.

Parent training sessions can implicitly place pressure on the parent "to perform," which creates additional stress and tension for them when interacting with their child. The parents often feel that they are being evaluated. The professional must, at all times, attempt to increase the parents' confidence in working with the child and arrange successful situations that will reinforce continued involvement.

A factor that can easily be forgotten in a parent training model is the need to respect and understand the current ways of doing things in the home. For example, parents may place their children in walkers before they are physically ready. This can be counterproductive to the child's development. From the therapist's perspective, the parents appear to be "disobeying" their requests not to use the walkers. To the parents, the child in the walker appears "more normal" and is allowed a greater degree of independence, which is reinforcing to the parent. Unless therapists or educators can find out why certain patterns persist and replace them with appropriate behaviors, parents are likely to resist changing the way they do things.

Parent resistance may also be part of the mourning process that accompanies the birth of a handicapped child (Ross, 1964). Denial and anger can subvert the educator's or therapist's attempts to teach a parent to train his or her child. If the parent doesn't believe there is a problem, he or she will not be likely to be cooperative in implementing solutions. If a parent is angry at "the powers that be," he or she may also be angry and resentful of any authority figure involved with his or her handicapped child, including the educator or therapist.

Some parents resent the added burden of learning to teach their child. Their lives already seem full of

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caretaking demands. The need for them to teach is one more sign that their child is different, contributing to their feelings of sorrow and depression. The professional must remember that handicapped children may be hard to love and that the parents may have ambivalent or rejecting feelings toward the child. Teaching a parent to teach a child they have come to reject can be counterproductive.

Some mothers may react toward the birth of a handicapped child with a sense of incompetence and a loss of self-esteem. All that the mother already knows about raising her child now becomes insufficient. In fact, doing what comes naturally may be counterproductive. In addition, she often has guilt feelings that somehow, she caused her baby's problems. During training, her sense of incompetence may even be heightened. The parents are told that their child will not make maximum progress without their assistance. Once given this message, they are then trained by skilled professionals. Already feeling incompetent, they compare their initial awkward attempts at handling their child with the seemingly magic hands of the therapist or with the polished skills of the educators. The parents may begin to feel powerless, impotent, and hopeless in this situation, and may fear that they will never be able to do all those things, so why bother? This additional stress is placed upon already-burdened parents and the nature of the parent-child relationship is altered.

The professionals' understanding that parent training can have a detrimental effect on the parent-child relationship is important. For example, when parents are taught isolated techniques, they do not necessarily understand the importance or relevance of those techniques. Then when they try to implement them at home, the normal routine may be upset, or the child may become

distressed. If parents are not sure why the task is important, or do not see immediate results, they may abandon the teaching activity when it becomes difficult for them. Additionally, the family situation and burdens are often not taken into account by professionals. Quite often parents may be asked to do more than their time or resources allow.

By focusing on the "parent as a teacher," professionals influence the parent-child interaction. The sources of pleasure for parents of handicapped children can change. For example, a study by Jones (1980) compared mothers of Down's Syndrome children with mothers of nonhandicapped children. When asked what they enjoyed most about their children, the mothers of Down's syndrome children tended to refer to successes in teaching situations. The mothers of nonhandicapped children frequently referred to enjoying their children for themselves and enjoying their company. The mothers of handicapped children tended to be more directive in interaction with their children and teaching was frequently quoted as an essential part of the interaction process.

A study by Kogan, Tyler, and Turner (1974) compared mother-child interactions of children with Cerebral Palsy while the mother and child played together and while they were engaged in therapy. While performing therapy, the mother and the child showed greater amounts of negative behavior (i.e., control, hostility, intrusion, ambiguous affect, negative voice, and content) than when they were only playing. Interestingly, the mothers became excessively controlling in the work situations. Furthermore, the behaviors persisted over a two-year period, demonstrating that they were not temporary reactions to a new situation. And even more alarming was the decline in friendly, warm, and positive behaviors during play sessions.

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In essence, isolated skill training for parents is often not fully effective (Bricker & Casuso, 1979). Perhaps even more important, it can have deleterious effects on the parent-child relationship. In a review of early intervention programs from 1965 to date and the emergent research from these programs, Gordon (1975) concluded that: "Simply teaching parents a particular narrow skill, or concentrating on teaching the child a particular performance, is not what it is all about" (p.16). Training parents to train their children is a viable channel for parent involvement; however, the approach does not work uniformly well with all parents and can even have a negative influence on the parent-child relationship.

Parent Counseling

Parent counseling is a second mode of involving parents in enhancing the development of their handicapped child. Over the years the intent and form of parent counseling has differed, depending upon the particular counselor, and has ranged from individual psychotherapy to informal social gatherings.

Many counselors have as their goal to assist the parents through the mourning process that usually accompanies the birth of a handicapped child. It has been suggested that parents need to mourn the loss of the normal child that they imagined. According to this theory, parents pass through stages similar to those of a person who knows he is dying or who has experienced a major loss (Baum, 1961; Ross, 1964). Emde (Note 1) suggests that if parents do not complete the mourning process, they are unable to love the child fully.

Parents of handicapped children report that they experience negative reactions including guilt, shame, anger, fear, depression, anxiety, ambivalence, frustration, hostility, resentment, loss of self-esteem, helplessness, feeling out of control, and hopelessness (Featherstone, 1980; Roos, 1963; Wright, Note 2). Counseling has been directed at facilitating the expression of these feelings, providing a forum for nonjudgmental acceptance, and reassuring parents that these intense feelings are normal reactions to having a handicapped child. The intensity of these feelings, if seen apart from the precipitating incident of having a handicapped child, may seem pathological; however, they are common reactions of parents with handicapped children.

Individual and/or group psychotherapy have also focused on parent growth, including, but not limited to, reactions to having this child. The birth of a handicapped child is seen as a crisis that brings to light parent coping patterns, both adaptive and maladaptive. The need to resolve the feelings accompanying the birth of a handicapped child can serve as impetus for deeper personal growth. The crisis can contribute to rapid growth simply because the problem cannot be ignored and parent coping patterns must be developed. Psychotherapy "teaches" long-lasting life skills beyond the immediate problem of coping with the birth of the child.

Group support for the parents of handicapped children has been another goal of counseling. Most often parent support groups are organized so that parents of handicapped children can gather to talk about their experiences and feelings. Parent support groups are sometimes led by a professional therapist or counselor, a program staff member, or the parents themselves. These support groups reduce the sense of isolation often experienced by these parents by providing a social setting in which it is

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acceptable to discuss their handicapped child. Parents report that participating in a group can reduce the feeling of Why me? They reason: All these other nice, respectable, healthy, intact couples had the same thing happen to them. If it can happen to them, it can happen to me.

Parent support groups also offer a forum for exchange of resources, information, and practical advice pertaining to parenting a handicapped child. In some instances, the support group serves almost as an extended family, providing encouragement and information.

Parent counseling also includes advising or instructing parents on how to determine their child's needs and how to find services to meet those needs. Training parents to become advocates for their child, by informing them of their legal rights and by discussing strategies for moving bureaucracies and systems, is another goal of parent counseling. Frequently assertiveness training is offered in advocacy training.

Parent counseling can become educational by setting a focus on topics such as behavior management and other parenting skills. Educative counseling for parents of learning disabled children has also included instruction in the 3Rs of routine, regularity, and repetition (Adamson, 1972), and has often been offered in conjunction with the child's treatment program. Counseling can increase parental understanding of the educational, social, and psychological processes involved in their child's individual educational plan (McWhirter & Cabanski, 1977) and facilitate school-home communication (Bricklin, 1977). Counseling, in conjunction with the child's treatment program, often focuses on modifying feelings, attitudes, and approaches which may be harmful to the child's optimum development (McWhirter & Cabanski, 1977). Topics within

child-centered counseling are usually confined to those feelings or themes related to the child's handicap and not to other areas of the parent's life. One strategy used in the child-centered approach is interpretive counseling. The counselor assists the parent in interpreting or decoding the child's behavior in terms of his or her underlying feelings (Adamson, 1972; Bricklin, 1977). This allows the parents to understand better their child's behavior and the feelings that may generate that behavior. Home visitors have also provided counseling for parents of handicapped children. A home visitor with a social work background can provide a blend of supportive counseling and practical guidance for the family (Fraiberg, 1975).

Case management and social service functions constitute parent counseling in some programs. Parents are assisted in accessing financial, medical, and psychological community resources. Assistance in household management and career development has also been offered to parents of handicapped and disadvantaged children (Levitt & Cohen, 1976).

There are both positive and negative aspects to parent counseling, both for the parent and the child. One negative aspect is the assumption that service providers, family, and friends sometimes make. They may label parents as overreacting, aggressive, hostile, resistant, or rejecting. They may also view parents as unrealistic people who either smother their handicapped children in overprotectiveness or totally reject them. They may also accuse parents of ignorance or denial of the truth. For example, if parents shopped for services for their child, they were seen as not realistically accepting their child's handicap, rather than as searching for answers and quality services.

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So it can be seen that parents of handicapped children find themselves in a bind. Barsch (1968) aptly depicts:

If the parent is militantly aggressive in seeking to obtain therapeutic services for his child, he may be accused of not realistically accepting his child's limitations. If he does not concern himself with efforts to improve or obtain services, he may be accused of apathetic rejection of his child. If he questions too much, he has a "reaction formation" and may be oversolicitous. If he questions too little, he is branded as disinterested and insensitive. (p.8)

On the positive side, parental counseling has been shown to lead to reduced rates of institutionalization for handicapped children (Graliker, Koch, & Henderson, 1965) and to improved chances of a family's maintaining the child at home. Also, counseling of parents of learning disabled children proved to be a valuable treatment as an adjunct to services of a special class for tutoring of the learning disabled child (Baker, 1970).

If the child's maximum development is a goal, then parent counseling alone is not a sufficient mode of parent involvement. It improves the parents' attitudes and resolves feelings, but does not necessarily translate into improved child functioning. The parent still may not have skills that facilitate the handicapped child's development.

While counseling is effective in assisting parents through mourning stages and toward acceptance of their child, it does not necessarily translate into improved performance in the children (Tymchuk, 1975).

Parent-Child Interactions

The third approach to parental involvement revolves around the mother-child interaction. Based upon child development theories, practitioners feel that the mother-child interaction could be the basis for enhancing the child's cognitive, language, and affective development. Several studies have looked at the relationship between interactions and later child development. In these studies interactions between mothers and three-month-old children were found to correlate significantly with teacher ratings of the children's social competence as much as three years later (Bakeman & Brown, 1980). Clarke-Stewart (1973) found continuities between early interactions and later development in lower socioeconomic status children. Tronick and Adamson's (1980) research suggests that mother-infant interactions foreshadow future modes of communication and action. This hypothesis is supported by Bruner's (1978) studies, which indicate that language acquisition occurs in the context of an "action dialogue" in which there is joint action of both the infant and the adult.

In developing the parent-child interaction approach, professionals reasoned that if interactions could be enhanced, then the resulting development would also be enhanced. This approach does not focus on parent teaching or child therapy, but rather on the reciprocal relationship of the parent and the child, which begins at birth. The infant gives cues to the parent, who interprets the cues and responds. The parent then gives signals that the infant gradually learns to "read." "The reciprocal reading and responding to each other's cues forms the core of a complex interactional (or transactional) system" (Bromwich, 1981, p. 9).

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Intervention in the parent-child interaction also differs from behavior therapy because the mother's therapy is integrated with the child's. The child is seen as a participant in mother-child conflict and not as a passive recipient of reinforcement. Interaction therapy or coaching does not include step-by-step instruction, but rather the modeling or presenting of basic patterns in response to viewing the parents' interactions and demonstrating appropriate ways of interacting with the child (Seitz & Terdal, 1972).

When the child is handicapped, parent-child interactions may be affected. Stone (1975) comments:

When the child's biological dysfunction affects the feedback, the responses he makes to his mother, their ability to establish a communication channel may be delayed or prevented. The mother's "doing what comes naturally" may not lead to the establishment of parenting practices which are helpful to the child. The child with a low level of activity can be seen as "good and undemanding" and can be left unstimulated in his crib. The infant who stiffens and is unable to mold his body to that of the person who is handling him can alienate the most loving mother. (p. 17)

The ways in which a parent of a nonhandicapped child finds pleasure in interaction are often not available to the parent of a handicapped child. Even feeding a handicapped child--normally a warm, rewarding experience with a nonhandicapped child--may be a source of frustration for both mother and child. The handicapped child may not give out cues that are easily read by the mother and/or the child may not be able to understand or respond to the mother's responses, which, in turn, can contribute to less than satisfying interactions.

The parent's emotional state and reactions to the handicapped child may also influence the interaction. A mother who is depressed is not likely to have the emotional resources to respond to the handicapped child's cues or to interact playfully. A mother may feel guilty about her negative feelings and "force" a strained interaction. Or, frustrated by a delayed or hypotonic child, she may overstimulate the child in attempts to get the child to respond.

Studies have documented the differences in interactions between mothers of handicapped children and mothers of nonhandicapped children. Kogan (Note 3) concluded that mothers and their handicapped children displayed higher negative and lower positive affect as compared with parents of nonhandicapped children. Kogan and Tyler (1973) found that mothers of physically handicapped children demonstrated greater assertive control and warmer behaviors than mothers of nonhandicapped children.

Parents of blind children present yet another facet to the parent-child interaction. Imamura (1965) found that blind children had more interactions with their mothers and fewer with other children, and more verbal interactions and fewer self-initiated interactions than sighted children. The blind children's interactions were more social and help seeking. Fraiberg (1975) taught parents how to interpret and respond appropriately to their baby's hand and body language and vocalization patterns.

Parents of children with developmental delays have fewer interactions with their children (Thoman, Becker, & Freese, 1978; Vietze, Abernathy, Ashe, & Faulstich, 1978) than parents of nonhandicapped children. Kogan, Wimberger, and Bobbitt (1969) described the interactions of mothers and retarded children as "both members doing nothing together."

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Yet the same study found that mothers of retarded children showed great warmth and friendliness.

The emphasis on parent-child interaction is a fairly recent one. Most of the literature concerning parent-child interactions has been directed at examining the components of interactions, defining the discrete steps in an interaction, and the process. There is little that defines a "good" interaction and describes actual interventions that can be utilized for training programs. Some representative studies are presented.

Training programs have been demonstrated to be effective in enhancing the mother-child interaction (Bromwich, 1976; Kogan, Gordon, & Wimberger, 1972). Mash and Terdal (1973) designed programs to enhance the interaction for parents and their retarded children which proved effective in modifying the play behavior of the children. The programs resulted in decreased mother's directiveness and control through use of commands and questions, as well as increased interactions. The mothers learned greater stimulus control over their children and the children responded more appropriately to their mother's actions than they had previously. The mothers also altered the frequencies of various behaviors and learned to respond contingently to various behaviors of the child.

Seitz and Terdal (1972) worked with parents of retarded preschoolers. Their program produced significant changes in parent-child interactions. The parents reduced maladaptive interactions and increased positive interactions by observing and modeling the child's therapist.

Kogan (Note 3) concluded that negatively toned interpersonal transactions between parents and their children with Cerebral Palsy can be averted and/or ameliorated by behavioral instruction and guidance.

But improvement in interactions was not accompanied by any measurable change in the child's skill development or independent function. In a further study with less severely handicapped children, a behavioral training program produced interactive and developmental changes. Parents could be helped to live more comfortably with the problems of raising a delayed child; however, the child's fundamental delay and inherent problems were not significantly ameliorated.

These studies demonstrate that the relationship between a mother and her handicapped child is more susceptible to faulty interactions than those of a mother and her nonhandicapped child. Although improved interactions can be facilitated, they do not necessarily translate to improved child performance. Whereas the child's play behavior may be positively influenced, physical or cognitive development does not appear to be as easily influenced. Interaction coaching or teaching is important and effective in some arenas. If the focus is on the child's overall development, however, simply facilitating the parent-child interaction is not sufficient to influence the child's total development.

Summary of the Three Approaches

The review of the three main avenues for parent involvement--training parents to train their children, counseling parents, and facilitating mother-child interactions--has presented the strengths and weaknesses of each approach. The purpose of parent involvement is to maximize the child's developmental progress and each mode of involvement is assessed on the basis of its effect on the child.

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In summary, training parents to train their children is effective when the parent has both a positive relationship with the child and the resources to implement the training. A danger with this approach is that the parent may become focused on teaching, rather than simply enjoying, the child. This training approach cannot be effective unless parents implement the programs, and many parents do not. Thus, parent training is effective when implemented, yet is not sufficient as the sole approach because many parents do not fully participate; those who do may find their relationship with their child negatively affected.

Counseling parents of handicapped children has been implemented in many different ways. There are, however, little research data available on its effectiveness. It has been shown to reduce institutionalization of handicapped children and to be effective in resolving parents' feelings toward their child. Parent counseling has not, however, been shown to influence the child's development directly. It does not necessarily change the way the parent interacts with or teaches the child.

Programs developed to improve mother-child interaction have also been shown to be successful in modifying the play behavior of children. The improved interactions do not, however, directly translate into improved child performance in the physical or cognitive sense, or improved parent acceptance of the child.

A Model of Parental Involvement

After reviewing the advantages and weaknesses of the three main approaches to parent involvement, a model of parent involvement that utilizes all three

approaches has been developed. The model is part of the Early Childhood Intervention Program, a program to prevent institutionalization of handicapped children. The parent model is based on Sameroff and Chandler's (1975) theoretical model of developmental transactions. In their model, prediction of outcome is a function of the continuing relationship between child and family, in which the characteristics of each are being continually modified by experiences with the other. Changes in the environment at one point in time (for example, a therapeutic intervention) may beneficially change the child such that the environmental reaction at the next point in time is more positive. An example is related to feeding training. A mother's negative response because of her inability to feed the child can be altered by improving her feeding skills. Once feeding is no longer the entire focus for her relationship to the child, she can begin to relate to more positive elements of the child's behavior, which can alter her entire perspective of the child.

In the Early Childhood Intervention Program, small groups of four to five parents (usually mothers) and their children meet once a week for half-day sessions over 10 months. The first hour and a half is spent in a transdisciplinary classroom co-led by two professionals of different disciplines (i.e., special educator and physical therapist) who teach the parents how to facilitate their children's development. During this classroom time, the parents and their children are individually video taped in a play situation. This tape is coded and analyzed to determine the nature of the parent-child interaction. If the interaction is found to be nonoptimal, interaction coaching is provided. Taping is done at three-month intervals. After the classroom group activities, the parents join a parent support or therapy group while the children receive more individualized therapy and attention. Next, parents return to the classroom and receive

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home programs to conduct with their children. A section of the weekly group is devoted to discussing the successes and difficulties in implementing the home programs. Thus, all three modes of parent involvement are incorporated into the program. The basic approaches of each mode are described in the following section.

Parent Training

In the model, parent training staff are sensitive to the parent's individual situation. Staff are aware of typical feelings and reactions that parents may have toward their handicapped child and the ramifications of these feelings. Staff are also aware of the importance of the mother-child relationship as a basis for child development. As much as possible, activities are made playful or are incorporated into the daily routine of feeding, dressing, bathing, and so on. Within the weekly program, parents are given information about their child. They are shown the prerequisite steps for developmental milestones so that they can understand why certain activities are important. They can thus learn to appreciate success in teaching each small step. If parents are focused on major milestones, that is, walking or talking, it may seem that their child is not making progress. They may not follow through with home programs unless they know why the program is important and where it is leading. An open channel of communication is fostered between the therapists, educators, and parents. Parents understand their responsibility to let the educator or therapist know when the home program is not relevant or realistic.

The educators or therapists use several approaches when teaching parents. They may use a doll to model or demonstrate the skill and then have the parents practice the activity. They may demonstrate the

skill with another child while the parents practice it with their own child. Whatever approach is used, each parent is given a notebook to record the activities. The therapists supplement the notebook with diagrams or snapshots of the activities to serve as reminders for the parents.

Parent Counseling

Parents are also offered counseling once a week for the entire 10 months. The parents meet in a small group of five to six mothers, which is led by a counseling psychologist or social worker. The purpose of the group is to help the parents cope with their feelings and their practical problems. The counseling goals are to remove blocks to maximum functioning, promote parental growth, and teach problem-solving skills. The groups do not focus entirely on coping with a handicapped child, but rather on facilitating the parents' development. The problem of having a handicapped child brings to light many aspects of the mother's life, including her coping style, patterns of interaction, ability to seek and accept support, and her relationship style. The problem serves as a crisis that often forces the parents to resolve faulty adaptive styles, develop new life skills, or strengthen current coping methods. Having a handicapped child often challenges the parents' values and belief systems. The counseling group addresses these larger issues as well as functional behavior.

The therapist has a plan of parent growth in certain areas and addresses the issues as they come up in the parent group. There is no prearranged sequence of topics; rather, the therapist maintains an internal checklist. This flexibility allows the parents to grow at their own pace and ensures a match of their current state with what is being addressed in the group. Topics are discussed as

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they relate to the parents' current situations. There are several themes that repeatedly occur, one of which is the role of mourning for the loss of the imagined normal child. Parents are informed of mourning theory in order to help them understand that their feelings of anger and helplessness are normal and that when channeled in a positive manner, they can actually facilitate the acceptance of their child's handicap. Parents are encouraged to express their feelings both within the group and also in their family or home setting. This expression is presented as a necessary process in the movement toward a fulfilling relationship with their child. Parents are often ashamed of their thoughts and feelings, and often deny them. The group creates a safe environment to communicate these thoughts and feelings and to identify other problem areas. The members assist and support one another in finding and using available resources.

Parent counseling seems to improve parent self-esteem, which in turn facilitates positive interactions and increases the confidence of the parents when training their child. The process, content, and effect of parent counseling is currently being evaluated by the program and will be presented in subsequent publications.

Parent-Child Interaction

The purpose of interaction coaching is to improve the mother's sensitivity to the child's cues so that she may respond appropriately. Interaction coaching is offered through 1) direct intervention with the mother and child by the interaction coach, who is a speech pathologist, or 2) consultation by the interaction coach with the teacher or therapist, who then works with the mother and child.

Upon enrollment in the program, each parent-child pair is video taped in a free play situation. The video tape is used to assess the interaction, based on the modes of communication the child uses and the mother's sensitivity to the child. The interaction is coded on a scale developed by Clark and Seifer (Note 4). From the assessment, it is determined which parents could benefit from interaction coaching.

The video tape is then viewed by the mothers and the coach. Simply viewing the tape often helps mothers see their child or themselves in a new light. Often they are surprised at the amount of agitation they display with the child. After viewing the tape the coach encourages them to talk about their feelings toward what they saw. Awareness of their feelings can help them understand why they do what they do. Once they understand their motives and realize how natural their feelings are in that situation, it seems to be easier for them to change their behavior. Interactive coaching is individually tailored to each mother and consists of a few (three to six) sessions. The mothers and their children are taped every three months to trace their progress and to see if they need different interventions as their child grows older and changes. The mother's problems or "errors" vary. One common error is that the mother does not wait for her child's response. She may over- or understimulate the child, or she may be unaware of the child's cues and respond to them inappropriately. Another mother may be too forceful or controlling.

Interaction coaching is provided to affect faulty or nonoptimum interaction styles. Coaching may consist of teaching the mother to take turns with the child. If the mother needs to slow down, she is asked to imitate the child, which helps her get in touch with the child's rhythm, interests, and initiations. If a mother does not interact with her

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child often or well, she may need to be taught baby or children's games. When teaching how to play games, the coach does not demand that the mother initiates the game precisely as demonstrated. The mother's personal style is respected, allowing her to become more relaxed.

Mothers are also taught to "read" and respect the babies' cues. Gaze aversion tells the mother that the baby is either overstimulated, disinterested, or interested in something else. A mother of a visually impaired infant may need to be trained to read the child's hand movements and vocalizations rather than visual cues (see Note 4).

Case Study

The implementation and interplay of the three modes of parent involvement in this model are demonstrated in the following case study.

Background

Geneva is the 40-year-old Hispanic mother of Maria, a child with Down's Syndrome. When she came to the program, Maria was 1-1/2 years old and had not received any therapy or intervention. Geneva is a dedicated mother who also works full time on the second shift at an automobile factory. Geneva took to heart the importance of training her child and worked with her faithfully and often. She relished the teaching role with her daughter.

The video taping of the parent-child interaction was a startling revelation to the staff. Geneva was controlling and almost looked abusive. As the child would pull away, she would squeeze her more

tightly. Although Geneva was a dedicated teacher and therapist for her daughter, she treated the therapy sessions as work. Her verbalizations reflected this attitude as she addressed Maria with comments such as: I'm going to report you to the union if you don't straighten up, or Keep working, it's not time for your coffee break. When Marie resisted her mother, which happened more and more frequently and became more forceful over time, her mother would become even more controlling. The same behavior was seen both in free play and in therapy situations. Interestingly, Maria did not have eye contact with her mother. Emotionally, Geneva had accepted the birth of her child very matter of factly and had become action oriented, finding an intervention program and other resources. She revealed little of her feelings of hurt, disappointment, or anger. When she did describe her reactions or situations, they were devoid of affect, even though she said she felt some emotion when questioned by the staff. It was evident that she cared about her daughter and loved her; however, there was little warmth and softness demonstrated toward her child. She handled her daughter as she did most of her life: capably, matter of factly, and in charge.

Interventions

Parent Training. As training progressed, Geneva learned the skills necessary to work with her child, yet her role as teacher almost supplanted her role as mother--her teaching success became the source of satisfaction in her mothering. The co-leaders of the intervention program became alert to this through feedback from the interaction coach. They began to introduce home activities for Geneva that involved more playful games. They also gave her home programs that could be utilized in daily activities so that the exercises could be worked into the daily routine.

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Interaction Coaching. At the same time, Geneva received interaction coaching. Because Geneva was out of synchrony with her child's rhythm, and seemed unaware of her child's initiatives and interests, she tended to be very controlling. As a result she was encouraged to establish rapport with Maria by imitating her. This technique provides the mother with an opportunity to get in tune with her child, while limiting the amount of control she can exercise. It helps the mother slow down enough to become aware of the child's interests and initiatives. It also increases the child's awareness of her environment, and the natural consequences for her behavior. When Geneva imitated Maria in a free play situation, Maria looked up at her mother and squealed with delight.

Sensitivity was shown for Geneva's individual interests by the staff's asking her what she enjoyed doing herself, to which she responded, dancing. She was encouraged to dance with Maria, an activity that Geneva found fun and felt very easy and natural doing. This activity helped Geneva realize the importance of enjoying an activity and sharing it with her child. In these activities, Geneva reported that she did fine until she started talking. She became more controlling and quickened her pace when she talked to Maria. She was asked not to talk until she felt there was reciprocity in the interaction. A further suggestion was for Geneva to try to convey warmth through her hands, which she did through gentle stroking and massage. Geneva responded to the coaching with relief, and immediately changed her behavior with Maria.

Counseling. Through group counseling, Geneva was encouraged to express her feelings about having a Down's Syndrome child. Her practical acceptance of her child had been very adaptive, but covered up some of the feelings of ambivalence that were evident in the video taping and handling sessions.

She was not initially able to take delight in the uniqueness of her child and was unable to express her love in soft, affectionate ways. Geneva did not demonstrate affection easily, so she was encouraged to find comfortable ways to express her caring. As she began to express more of her negative feelings toward Maria, she was also able to express more of her positive feelings. Rather than seeing Maria as a duty, she began to appreciate various aspects of Maria's personality, which allowed her to appreciate Maria as the child she really was.

In the case of Geneva, parent training alone was obviously not sufficient. She had incorporated the techniques of education and therapy well, almost too well. Her role as teacher/therapist had begun to alter the parent-child relationship. When interaction coaching was given to Geneva, it assisted her in finding ways to enjoy her child. She became more "in tune" and in synchrony with her child and was able to follow Maria's lead. Maria's resistance lessened as Geneva's controlling lessened, and vice versa. Gradually Geneva was able to enjoy Maria and as her ambivalence lessened, she became more effective as her child's therapist. As a result, her therapy became more natural and playful. Through counseling Geneva became aware of her guilt for having a child at a late age. When Maria was born with Down's Syndrome, her guilt compelled her to work hard to make up for her "mistake." With counseling, she was able to let go of much of the guilt, to express her feelings of aloneness, sadness, and anger, which moved her toward accepting Maria fully. As Geneva gave expression to her true feelings about having Maria, she reported feeling more free to be a "loving mother."

From this example, the interplay and importance of the three modes of parental counseling should be evident. Each mode, by parental report, affects and

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assists the other. Together, the whole seems to be bigger than the sum of the parts. It is our hope that research will bear this out.

Conclusion

Parent involvement in the education of the handicapped child has been recognized as a necessary activity if the child is to make maximum progress. The question has been how to involve parents in the education of their handicapped child. A review of the three modes of parent involvement--training parents to train their children, parental counseling, and facilitating parent-child interactions--had indicated that no one approach is sufficient in itself for maximum impact on the child's development.

Parent training, when parents are able to implement it, does affect the child's development; however, it may alter the nature of the parent-child interaction. Parent counseling assists parents in resolution of their feeling, but does not translate directly into improved child progress. Intervention for nonoptimal parent-child interaction is effective in improving the interaction, but does not necessarily improve the child's overall development.

The proposed model of parent involvement synthesizes all three modes, in the belief that their interplay supports the effectiveness of each part as well as the total child and parent development. Our philosophy is that we cannot teach parents everything they need to know throughout their child's lifetime, but we can set the stage for future growth. Providing parent training along with counseling and facilitation of parent-child interaction provides this forum.

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Maximizing Evaluation of Handicapped Children by Integrating the Efforts of Parents, Child, and School

Albert Greenwood

The implementation of Public Law 94-142 defined the public school's role in evaluation, identification, and placement decisions regarding the handicapped child. Such definition, intended or not, has implied that school personnel will carry primary responsibility for the quality of evaluation experiences during the child's involvement with special education. Such responsibility is becoming burdensome in the midst of expanding legal arbitration regarding the public school's evaluation and identification of handicapping conditions. In fact, the entire process of evaluation seems to be receiving more and more attention as funding for special education decreases and parental awareness of child's rights to appropriate education increases dramatically.

While it is certainly the school's role to facilitate appropriate evaluation and placement, to enhance the quality of such processes requires extensive participation by members outside the school. PL 94-142 has provided some opportunity for parent involvement in the identification process, such as the IEP Conference, yet the expectation of their participation from a legal standpoint lacks clarity, and thus, responsibility in their contribution seems diminished. The child has received little, if any, attention as a responsible contributor to the evaluation process and subsequent program design.

There seems little question as to the impact parents may have upon their child's educational experience. Evidence suggests that the family is critical to the child's success in the classroom (Bricklin, 1970; Karnes, & Zerbach, 1972; Karnes, Zerbach, & Teska, 1972), in skill acquisition (Friedman, 1978; Ross, 1976), in learning behavior (Bloom, 1981) and in attitudes and motivations toward learning (Gordon, 1971; Green, 1978; Haring & Bateman, 1977; West, 1978). This is particularly true for the handicapped learner, (Abrams & Kaslow, 1976; Edgerly, 1975; Kaslow & Cooper, 1978).

Increasingly we are becoming aware of the importance of a child's attitude and motivation as significant factors in educational success (Wong, 1980). Reports on a child's style as a learner (Sabatino, 1979), his or her approach to the special education setting, and his or her psychological approach to problem solving (Kagan, 1966; O'Leary & Drabman, 1971) suggest that the child's own contribution to the learning setting will have measurable impact.

From an assessment standpoint, we know that more comprehensive evaluation and identification of potential academic problems can occur with parent involvement and with attention to the child's social

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environment (Sundberg, 1978; Schaefer, Note 1). The complex interaction of a child's cognitive competence, unique personality, type of academic setting, teacher behavior, and family interaction pattern all seem to affect performance in the classroom. Rarely can learning problems be explained by a singular area of deficit or a simple cause-effect relationship (Ross, 1976). The evaluation and certainly the remediation of the handicapping condition involve many variables outside the realm of basic academic issues; therefore, the notion that problems in school should be handled "by the school" sorely needs revision.

With such information before us, it is important to look closely at the appropriateness of school personnel assuming such a large responsibility for the quality of evaluation procedures and, more globally, the child's success in the special education experience. Although PL 94-142 has provided some useful guidelines for upgrading services to handicapped children, the potential of the evaluation as a contributor to a child's success seems to have been minimized.

There seems to be little doubt about the importance of parents, the child, and the school working more closely together. The development of productive working relationships between family members and school has long been a target of special educators. This is appropriate in light of the information we have about the potential contribution of parents and child to the entire special education experience. Yet as we have attempted to elicit more involvement, three factors seem to occur again and again. First, the notion exists that it is difficult to get parents to participate in special education (Karnes & Zerbach, 1972); second, most of the activities that involve parents occur in isolated situations, such as a parent-teacher conference or parent

involvement in the remedial classroom. Third, rarely are there attempts to integrate efforts of parents, child, and school together throughout a child's special education experience.

This paper will focus on the value of equally shared effort and thus responsibility between parents, school, and child in special education intervention. We are aware of how difficult it is to establish working relationships, and furthermore, to have such relationships occur in an integrated fashion. In rare situations the parents, school, and child can develop an integrated and productive process with little more than a request of their participation. It is more often the case, however, that the complex issues surrounding the educational program for a handicapped child result in a variety of questions, misperceptions, psychological defenses, and discordant goals. The presence of these factors demands a sensitive and planned approach in gaining a cooperative effort. We must work toward achieving an effective level of participation among parents, child, and school.

A model for obtaining such participation is proposed in the initial sections of this paper. On a philosophical basis, the model is proposed to stimulate thinking about the complexity of special education intervention. Pragmatically, with variation and adaptation it may provide a useful structure for direct clinical intervention. In order to provide quality of experience, the parent, child, and school must work as a team to have a sense of awareness about the intervention, an understanding of its procedure, and agreement towards its goals. Only then can the participation of all three become useful.

Useful participation should have continuity throughout the special education experience. Unfortunately, attempts to establish increased

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involvement by parents and child often occur in isolated areas and have tended to exclude preliminary activities involving a child's evaluation. Thus the intent of this discussion is to first provide the reader with a framework for developing cooperative effort (use for participation), and then examine how such a theory may be applied in the early phases of intervention that is, evaluation and continue to operate through the steps necessary to achieve successful remedial intervention.

Obtaining Participation

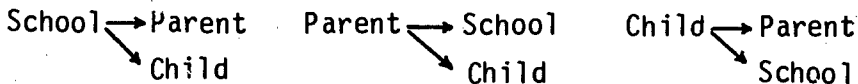
This model for eliciting participation has drawn upon many of the ideas of other professionals interested in improving the method by which families and schools could interact. The procedures here, however, are intended to be used over a broader range, and by more extensive application they will strengthen the entire service delivery.

Figure 1 indicates the steps in developing useful participation. It is important to consider that these steps are prerequisites to productive effort between families and schools. It is unlikely that participation as defined in this paper can emerge without an attempt to work through the various steps. In addition, the process of working through these steps will clarify the direction that the participation may take. It is important to realize the interdependence of these steps in producing the desired outcome; while each level represents a discrete activity, one level is a necessary contributor to another. The success of Level II activities (understanding) depends upon the degree to which appropriate awareness activities have taken place in Level I. Similarly, the quality of

agreement and commitment to a special education intervention obtained in Level III may be compromised without appropriate awareness and understanding occurring at Levels I and II. The model, therefore, presents activities in a hierarchical fashion. It is possible, however, to move back to lower levels in the hierarchy if activities in Level II or Level III are being compromised by failure to obtain closure at preceding levels. Notice, then, that in order to maximize any level of activity, it is important to be able to move to a preceding level if there is an indication that closure was not obtained in that level of activity.

Level I

At Level I, a basic awareness of the factors leading to special education intervention first arises. This level is characterized by a sharing of basic information. The goal in this level is to make parents, child, and school personnel equally aware of information necessary to complete any one step in the special education experience. New information is typically brought to the attention of two members of this team by a third member. This may occur via a progress report, parent-teacher conference, a child's behavior, or a verbal complaint. The following diagram indicates the didactic nature of such a communication.



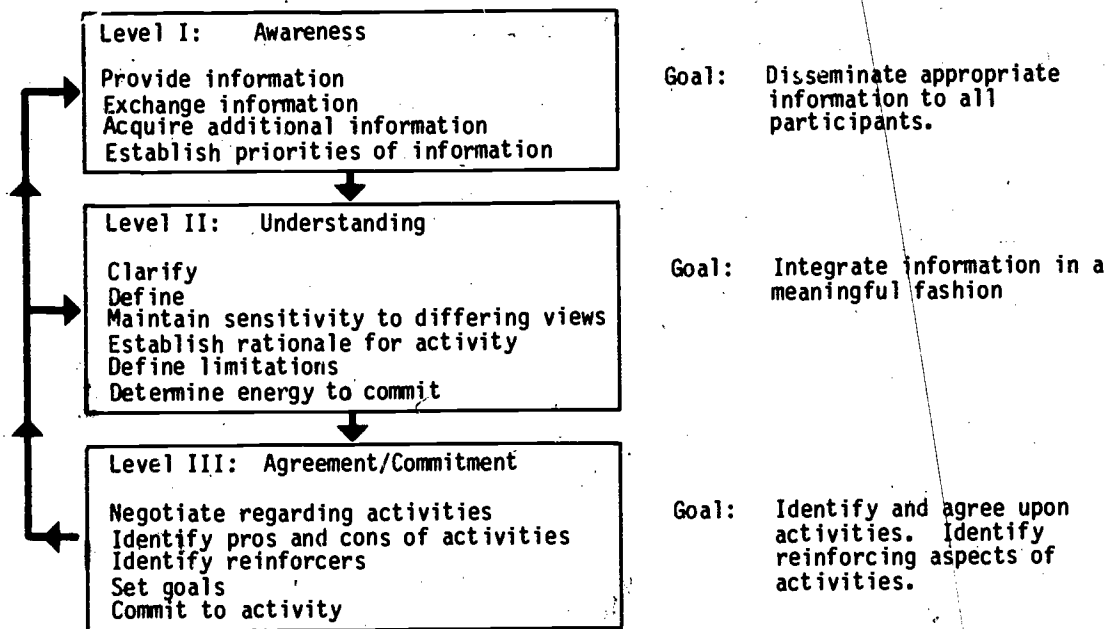
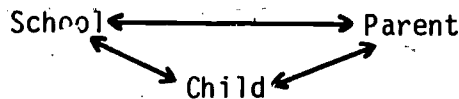


Figure 1. Useful Participation Model

The initial communication that brings information to the parents', child's, or school's awareness is directional in nature, that is, expressed by one member toward the other two. The nature of this communication, however, must change rapidly in this first level in order to provide reciprocal exchange of information. This reciprocal exchange is a critical component that allows not only the original information to be brought to the fore, but also additional, complimentary, or novel information that may pertain to the topic at hand. The following diagram represents the multidirectional exchange of information that needs to occur as all three members increase their awareness about the information that has been brought to their attention.



As noted, the goal of this first level is a sharing of information. Allowing exchange among all three members not only provides for an equal distribution of information, but also accomplishes several other important tasks. First, open communication between the three reduces the chance for secrecy and subsequent confusion about various procedures that may be used in the intervention. Second, the chance for additional concerns to be brought up is available. Third, by reaching a level of shared awareness, it is more likely that appropriate procedures for resolution will be identified. As an example, the identification of concerns on the school's part may be novel to the parents or may, in fact, have been something they have been thinking about for a long time, but were afraid to bring to the school's or child's attention. Similarly, the

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child may be aware of difficulties in school, but unaware that others have noticed the same. The school personnel may be concerned about a specific behavior, but may find a simple explanation when information is shared between the child and family.

Once all information has been introduced, it is then useful to have each member rank the information in terms of his or her own priorities. This process helps to identify what may be most valuable to pursue. This will also direct future discussions and activities that will occur at Levels II and III.

Level II

Once we are assured that all three members of this team have appropriate amounts of information, and thus awareness, there is a need for all to understand the parameters of the issue(s) involved. This constitutes activity at Level II: Understanding. How is it that this concern came about? How aware, initially, has each member been about the item of concern? How will each member react to the fact that a concern has been brought to his or her awareness? This is a time to explain and disseminate information, to understand not only the origin of the concern or planned intervention, but to appreciate the impact that it might have upon each member of the team. While we often see the school disseminating information to the parent and child, we cannot underestimate the value of the parent's and child's perspective on the item that has been brought to their awareness. This is particularly important if one is to recognize the differing value systems that each participant may have, and thus, how he or she may view the problem. Before gaining any sort of integrated effort for the intervention, we must make sure that information is obtained from each member, and the potential for variance due to age, philosophical stance,

psychological investment, and certainly many more factors is accounted for.

The goal of activity at this level is to promote discussion in a way that ensures a meaningful understanding of all information that has been presented in the Awareness level. As such, there is a need for open exchange of feelings, questions, or attitudes about information being discussed. If novel information is being presented to any one member, sensitive explanations need to occur. During this phase we are not seeking agreement about what is being discussed, only the chance for the discussion itself to occur. That freedom allows for an understanding of the information, as well as an appreciation of each participant's views. This consolidates the working relationship that is necessary to move forward in the special education experience.

During this time the benefits and liabilities of any activity, a divulgence of information, or any change that might come from new information are discussed. In this way, all members can see the potential advantages and disadvantages of their future involvement. Focusing on advantages will help to elicit commitment and make a contribution more effective.

Level III

Level III, Agreement/Commitment, is highly dependent upon success in the development of awareness and understanding among the three members. Here the formulation of intervention procedures will occur. More importantly, if success has been achieved at Levels I and II, a commitment to an activity is more likely to occur. Not only will there be greater understanding, but the agreed-upon activity will have some mutually reinforcing aspects to each member of the group.

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The Agreement/Commitment Level is characterized by negotiation. There is a need for a mutually supportive atmosphere and a great amount of give and take. The participants must decide what interventions are most important and appropriate for the child, how they will come about, and what they will mean to all concerned. There will be obvious attempts on some member's parts to convince others of the need for certain activities. It is essential that each member listen carefully to the other, and while advocating for his or her own particular needs and wishes, be willing to compromise in an effort to reach common goals. The essence of this level is to agree on something. From this agreement is developed an active plan for any number of intervention procedures. Establishing a reinforcing element for all members in whatever activity is chosen supports the development of commitment as the planned activities are realized (emerging from prioritization in I, and discussion of benefits and liabilities in II).

Useful participation will only be achieved if there is awareness, understanding, and common agreement among the members of this team. While the reader may feel that this goes without saying, it is our experience at the Children's Program that parents and schools often do not reach awareness, understanding, and common agreement before special education activities are initiated (particularly evaluation). Most importantly, the prerequisites that have been outlined, if accomplished, can integrate and strengthen the entire special education effort. Failure to reach the goal of each step can result in disparate intervention goals, varying levels of psychological investment (lack of commitment), and, most importantly, a lack of shared responsibility that might produce mutually supportive and reinforcing activity.

Before discussing how the model of useful participation by the team of parent, child and school may occur in evaluation activities, we need to examine the entire special education experience itself. We have identified the important and typical components of such involvement.

The continuum (Figure 2) identifies 14 activities, beginning with the initial display of concern that typically occurs from the school. The process ends with a child's placement in the special education setting and in receipt of remedial activity and review. Obviously, this is a gross representation of all the effort that may go into a child's involvement with special education, but for our purposes here it should suffice. The entire process has been divided into two phases; Evaluation and Placement. This is an arbitrary division; however, it does cluster activities into meaningful groupings. The reason for dividing this process into these phases is to isolate events that occur in the evaluation phase, which receives emphasis for the remainder of the discussion.

Evaluation Phase

The special education experience as a process, and the importance of evaluation within that process has been touched upon in the introduction to this paper. Due to the importance of both the concept of the special education experience as a process and the evaluation experience as it relates to this process, these areas will be discussed in more depth.

Although the 14 steps can be discrete activities, they relate closely to one another, and as stated earlier, must be considered a process. This process begins with evaluation procedures, but works toward

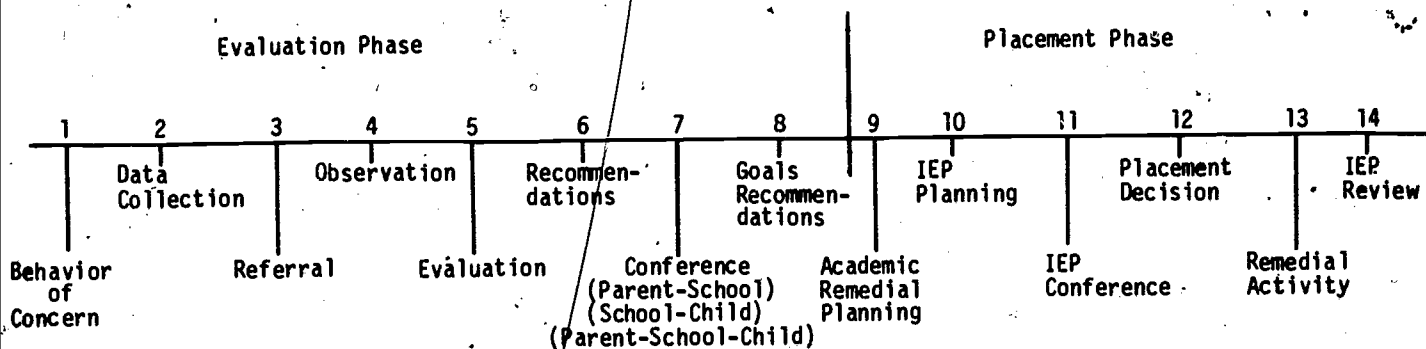


Figure 2. A Continuum of Special Education Activities

successful remedial intervention. The activities are actually additive in nature, in that any one event is enriched by the success of preceding activities. Diluting the potential of any one step along the continuum of intervention may compromise subsequent activity. Rarely would we perform step 5 (evaluation) without step 1 or 3. Similarly, a diagnosis (step 7) would be less than believable without step 5. If we agree that the success of the total process depends upon the success of each step, it seems reasonable to maximize our intervention from the very beginning of a child's involvement with special education. It is our contention that maximizing the entire intervention involves the participation of family, child, and school in these very first steps. The benefits are enrichment of subsequent steps throughout the continuum and an increased chance of realizing remedial success. Focusing on the Evaluation phase, then, seems appropriate because of its importance to the final goals.

Even though this phase is so important, the literature related to parent and child involvement in special education typically is focused on events in the latter part of the Evaluation phase and in the Placement phase. Another reason for focusing on this area then, originates from the lack of procedures available for initiating this early involvement. It is generally the case that parents and child are participants in formal evaluation, but such participation can best be described as passive; information is usually extracted from them. The reciprocal exchange of information obtained by participation as a team is much less common in this portion of special education service delivery.

The third reason for focusing on the Evaluation phase is the immense amount of attention occurring in this area today. Large numbers of evaluations are performed on children in public schools as well

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as in the private sector. This testing is, in part, attributable to our expanding knowledge about problems in learning as well as growth of our evaluation technology. In addition, the previously mentioned mandates of PL 94-142 to identify children experiencing handicapping conditions has stimulated much testing (and differences of opinion) in the hope of appropriate identification. Improving the quality of our evaluations then, seems a reasonable objective, if not a necessary one.

If we examine the Evaluation phase alone, there are nine major steps that may occur in the order described in Figure 2, with modification depending on the particular service provider. The literature in education and psychology offers an abundance of information related to each of these steps. As noted previously, however, the information is usually focused upon types and uses of instruments the clinician can employ.¹ It is proposed that these activities can be enriched if the clinician utilizes the competencies and energies of the parents and child. With their early involvement, responsibility is more equally shared, evaluation methodology itself is improved, and the chances for remedial success are increased.

Let us examine several important steps in the Evaluation phase and observe the opportunities for and the advantages of early participation by parents, child, and school together. Keep in mind the necessity of engaging in the steps that lead toward useful participation, and the effort to integrate the involvement of individual members toward common objectives. Employing the model as each step in the special education experience is encountered, we not only maximize each of the discrete activities, but collectively gain a stronger movement toward active agreement and commitment in remedial intervention.

Behavior of Concern

It is usually the case that there is some concern on the school's or parents' part that is brought to the attention of the special education staff. Often the concern comes in the form of academic or social problems or some observable evidence that a deficit area or handicap exists. This has been identified as behavior of concern in Figure 2. The relationship and involvement among the school, family, and child begins here. We start to organize information according to the model, the first step being development of awareness.

An example of the complexity involved in the initial stage of awareness follows. A child is referred by the classroom teacher to special education for failure to achieve in mathematics. There is a concern on the school's part that the child may have a learning disability. The parents are made aware of the child's poor performance in math and it is found that they share concerns with the school. The school, however, may be interested in identifying a handicapping condition, while the parents may not be willing to have their child so identified. Additionally, the parents identify peer relationship difficulties observed within the neighborhood, of which the school is not aware. The child recognizes his difficulties with friends in the neighborhood, but is not aware of the level of concern that the school has about his math performance.

In this example, the original behavior of concern brought to awareness by the school is performance in mathematics. The parents share this concern, but also have concerns about their child's social adjustment. This may be new information to the school. Unless the school personnel have been open to an exchange of information, they may be aware of only math difficulties in the child's overall function. For the child, his math difficulties may

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have been recognized, but not perceived at the same level of concern as the school's. We also have seen that the school's awareness of math difficulties has led them to think about the possibility of a handicapping condition, yet even though the parents share concerns about mathematics, they have not been concerned to the point of considering that a handicap may exist. The development of awareness by accessing information from all members has brought out the many facets of the initial point of concern.

In our use of the model, as an initial procedure (corresponding to Level I) we concurrently access the parents' and school's concerns about the child. This is recorded on a simple grid (Figure 3). In addition, we gain as much information about the child's awareness of the problem at hand by parent and teacher report. More direct information from the child is obtained later in formal evaluation (to be discussed). The items brought to awareness are prioritized in order to assess the level of awareness and subsequent importance of each area of concern. In addition, a measure of the disparity among concerns is obtained.

Prioritization of the concerns allows us to move into Level II, that is, understanding among the participants. Assumption of common concerns is a significant error and all three must gain an understanding of each other's priorities. By discussing the origin of each member's concerns, insight is gained into the importance of that concern. Taking into account the differing value systems of each member may help all to understand the nature of the concerns identified. For each member to understand areas of consensus as well as disparity serves to focus subsequent activities in the Evaluation phase. Evidence becomes clear by this procedure as to what is foremost in people's minds. If too much divergence occurs, the common effort may be compromised. Movement toward a goal

of the school may be diluted by the parents' or child's interest in another area. In the example just presented, peer relationships have top priority for the family and child, while performance in the academic area of math is the prominent concern on the school's part. In this case we have consensus in certain areas of initial concern (math), but different, although not opposing, concerns in the area of social development. Accordant and discordant views can be discussed in terms of the advantages and disadvantages of further activity in any one area. Thus, the school may argue that attention to math difficulties will improve social/emotional issues, such as self-concept, and may be the most efficient way to pursue the concern. On the other hand, the parents may advocate for attacking the social difficulties directly, as they may feel it would bring a quicker resolution.

This is also a time to define new terms and expand participants' knowledge of what various special education activities may mean to each of them. They also need to understand the expectations of their performance related to activities that are being suggested, that is, how much of their time will this take, what will they have to do if they are to become involved? This brings us to the third step in developing useful participation, Agreement/Commitment.

Negotiation, particularly as it relates to potential disparities of concern, highlights the Agreement/Commitment step. The development of a consensus about what activities or intervention procedures should take place serves to integrate the efforts of the three and develop the desired team participation. Once methods or targets of the intervention have been agreed upon, goals can be set with an expectation that when they are met, each member will have gained something. This is the

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	Completed	Information	Parent Assistance	School Assistance	Social Development	Evidence of Medical Problems	Academic Levels	Psychological Development	Community Resources for Family, School, Child	School Staff Evaluation Inservice	Post-Evaluation Consultation	Assistance in Academic Planning	Family Support, Guidance	Identification of Handicapping Condition	Independent Evaluation 3rd Party
Family		1			2		3	4							
School							1			5	4	3		2	
Child			2	3	1							4			

- 1) Rank each member's concerns.
- 2) To be filled out by clinician

Figure 3. Concern Checklist (Example)

mutually reinforcing aspect of the effort, which should maintain interest and shared participation.

Continuing with the example, the decision may be made to put direct intervention in math aside for the time being and focus on the child's social difficulties. The parents may feel that this will offer the most immediate problem resolution. The child may also see help in this area as something worthwhile and have more interest in gaining friends and social comfort than in being identified as a problem learner. Furthermore, after engaging in the discussion, the school personnel may feel that social difficulties could have a great influence on the child's performance in math, because of lack of concentration. Thus, attention to the social areas may have a positive influence upon the child's academic work.

By clearly identifying what is felt to be important (Awareness/Understanding) and where people want to go with that information (Agreement/Commitment), we increase the potential for a common and focused intervention that will ultimately have the most reinforcing value for all involved.

It is important to recognize that all the activities described have occurred in the first step of the Evaluation phase, behavior of concern (see Figure 2). By utilizing the procedures described previously, the data collection, observations, and referral can become more meaningful and certainly enhance later steps, such as formal evaluation. Utilizing the model to develop useful participation in the initial steps of the Evaluation phase allows the formulation of the specific activity or goal. In other words, we have established some direction for subsequent steps. Therefore, utilization of the model in the first step is unique in that it has served the purpose of developing a goal for step 2, data collection. From here on, each time the model

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steps are employed, the Awareness level can bring information related to the goals started in the previous step. While this not only provides continuity throughout the various steps in the special education experience, it also focuses on activity and creates more pragmatic interventions.

Referring to our example, if a consensus has been reached that the child's social adjustment has top priority, more data would be collected about peer relationships at school than if math had received priority. In addition, observation could be directed at activities in the social arena, as opposed to observations of the child's behavior during math period. The focus of later referral may also be clarified; in this case, referral to a psychologist, as opposed to an education specialist, may be warranted.

It is not the intent of the model in this example to exclude the importance of math difficulties if the social adjustment is pursued. We must remember, however; that all problem areas cannot successfully be attacked at once, and in many cases, the division of energies dilutes the strength of the intervention. This is why we choose to place concerns in a hierarchy. As the focus of attention is on the item of highest priority, it is then possible to begin renegotiation procedures to attack the second area of concern in the hierarchy--math.

We must continually be aware of the potential for breakdown of common efforts as our team moves through the various activities in the special education experience. Reworking through the steps that will lead to and maintain useful participation helps to develop consistency of participation in spite of the varied activities that occur. In using this model, we find that renegotiation of agreed-upon goals occurs again and again as new information enters the system.

Formal Evaluation

Although the model can be employed in all Evaluation phase activities, for brevity, let us move to step 5: formal evaluation. Utilization of the model during the formal evaluation establishes optimum testing conditions by allowing the members to perceive themselves as part of the evaluation process rather than as recipients of a clinician's attempts to evaluate them. In this way we increase the element of responsibility to include more than the clinician. We gain increased awareness by all participants of the activities involved in the evaluation. It is our belief, however, that useful participation within the formal evaluation session is one of the most critical facets of the child's entire involvement with special education. It is therefore mandatory that participation by all members be carefully elicited.

Initially, we need to establish awareness about the evaluation itself. At this level the clinician typically facilitates discussion. Parameters of the formal testing, such as the nature of the evaluation, the instruments employed, and the type of information assessed, are made available to parents and child. The test instruments and procedures to be used during the evaluation should be explained to all participants. It is also helpful to introduce the person administering the test.

Continuing with our example, the clinician could begin the Awareness Level by pointing out that the evaluation would focus primarily on social behavior, friendships, and the child's feelings and attitudes about any number of topics. The type of instruments used to gather such knowledge (planned interactions, personality questionnaires, etc.) and their effectiveness in addressing everyone's concerns about the child's social relationships can be

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brought out. What the parents and child can expect from a test result, such as a measure of social adaptation or description of classroom behavior patterns, will clarify what new information may be brought forth. This is particularly useful for future work, when the group addresses any fears related to the new information. It should reduce potential resistance or defensiveness. In this example, knowledge about some academic skills may not be gained, and this fact needs to be explained to the parents and child. Priorities for the evaluation procedures, in terms of what methods will be used, where, and for what gain, can be established during this level.

Benefits of sharing information during the Awareness Level are 1) reduction in the amount of secrecy surrounding the evaluation, and 2) increased ability of all members to acquire information that can be discussed at the Understanding Level. This allows the parents and child to talk about upcoming testing and to question what to expect from the tests themselves and from the information the tests may produce. Exactly what kinds of information the participants can expect to receive may reduce misperceptions and subsequent fears about the testing. In addition, such a discussion can bring the limits of psychometric testing into realistic perspective. The advantages and potential disadvantages of formal evaluation and resultant data need clarification. Then the evaluation process can be structured in a manner that ensures the maximum amount of reinforcing value for the participants. This portion of the process is also a good time to review new concepts and procedures that, while familiar to the educator, may be quite foreign to the parents and child. Prior to our evaluations at the Children's Program, we have parents fill out a checklist in order to determine their familiarity with terms commonly used in special education evaluation. They have the

opportunity to indicate their desire to learn more about unfamiliar areas. Through discussion at this level, the clinician can take steps to ensure that the language used when explaining the child's test performance is understood by the parents. Similarly, the child can benefit from his or her increased knowledge about various types of disabilities or academic difficulties. It is important not to keep the child in the dark about all the activity that is taking place. The more we can increase the parents' and child's understanding of the testing session, the more we stand a chance to obtain valuable data and cooperation.

The third level of Agreement/Commitment to the testing itself will be more efficient if closure has occurred at Levels I and II. Sensitive, reciprocal discussion should have overcome potential resistance by the parents and child to a formal evaluation. Reaching agreement through negotiation to perform in certain activities in the evaluation session must include clarification of the role and thus, expectation of the behavior for each participant. Not only do the participants then know what to expect from testing, but also what they will have to do in order to improve the nature of the evaluation itself. Knowledge of the amount of energy that parents, child, or school can commit to evaluation procedures will allow each member to be sensitive to the amount of commitment that any one person may have when roles are defined.

While the clinician's role is to facilitate the testing, and to perform the major role in terms of the test administration, it is beyond the clinician's capabilities to perform a comprehensive evaluation without active participation from parents and child. The latter two then, must be able to see exactly what they have to gain by their participation and to feel that the outcome is dependent upon them as well as the clinician.

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By using the steps in the model prior to the actual evaluation, we can enter the testing itself with a shared sense of cooperation that will benefit all participants. The benefits may occur at different levels; however, they must be associated with the recognition of all members' shared contribution. We have thus expanded the notion of testing from a simple two-person interaction (clinician-examinee) to a process that requires cooperation among three members.

Formal evaluation produces new and substantial information and sets the stage for closure on the Evaluation phase. Remember that at any time new information enters the system, the chance for a breakdown in the working relationship increases. The abundance of new information from formal evaluation increases the importance of maintaining the useful participation previously acquired. How such information is utilized sets the tone for events in the Placement phase. We can, therefore, view the sharing of evaluation results as a critical transitional procedure leading to successful placement activities. The information exchange and goal setting also represent a culmination of all events in the Evaluation phase. Because the conference is so critical to validating prior efforts and enhancing the quality of activities to come, it is worthwhile to examine it closely.

Conference

The structure of the conference (step 6) itself parallels the levels in the useful participation model. Information is presented, then made meaningful, and finally, used to pragmatic ends. It is extremely important during the conference that movement back to preceding steps occur if there is any feeling that a particular level is failing due to lack of closure in earlier portions of the

conference. Perhaps more than ever, the conference needs to be considered as a process, as all activity in the conference is interdependent. The goals of the conference, that is, useful exchange of new information and development of meaningful activities, cannot occur with lack of closure in any one step.

Two important factors, time and level of affect, influence the nature of interactions and subsequent movement through levels in the model. These factors are introduced at the conference step because of the critical nature of the conference and the necessity of working through important information. In fact, these parameters need to be recognized at all points of intervention during the special education experience.

As the conference is really a culmination of the five preceding steps in the Evaluation phase, there is an immense amount of work to be accomplished. All participants must be goal directed, although not at the expense of sensitivity and reciprocity. We have found that a time period of 60 minutes is appropriate for an initial conference. This time limit obviously requires all participants to be on task. The reason for limiting the time is to control the amount of information exchanged, thereby reducing cognitive and emotional overload. If we are pragmatic during the conference, closure on all necessary activities can occur within the 60-minute framework. We must, however, leave the option open to continue working at another time if we are unable to finish during the original time framework. It is essential that closure be attained during each level in order to maintain participation, and if more time is needed to gain such closure, it should be taken. Rushing to gain closure can seriously compromise all prior efforts to develop useful and continued participation in the Placement phase. The clinician, in particular, must monitor his or her

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own tendency to divulge too much information, and thus to create potential confusion on the parents' and child's part. If we allow ourselves the flexibility of having a second or even third conference to discuss the information, we are able to present information in a manner that decreases potential confusion due to overload. We can assist all members in digesting new material and incorporating it into their own system of beliefs and knowledge.

The second parameter to be considered during the conference is the level of affect of each participant. Emotions typically run high during conferences. This is in part due to the novelty of the information being presented, and the potential impact the information will have upon each member of the conference. Elevation in affect among any of the members will reduce the capability of exchanging and remembering information. All participants must be given time to "hear" information that is being presented so that they can incorporate it into a realistic context. The clinician must be alert to signs of high emotion and defensiveness on the part of group members. Defensiveness and volitive or passive reactions may indicate that the information is not being absorbed. A high level of affect usually interferes at the second level (Understanding). Two factors may be occurring here: 1) because of personal anxieties, defensiveness, or values, the information may be simply unacceptable; and/or 2) the information may be received or "heard," yet be so powerful that the participant may need time alone to accept it. In either case, movement toward some agreement about future goals will be difficult until the information is heard and understood.

The intent of the first portion of the conference is to increase each participant's awareness. As an introduction, it is useful for the clinician to

outline briefly the structure the conference will take. This would include a presentation, verbal or written, outlining the three distinct portions of the conference: Awareness, Understanding, and Agreement/Commitment. The goals for each particular portion of the conference can be identified. In this way, the parents and child are aware from the beginning of the way in which the conference will progress. By describing the various phases, the parents and child will know what information is going to be discussed at what time and will have a sense of order about the conference. The facilitator needs to bring up the time limit and discuss the potential for information overload, as well as the need to integrate information and attain closure in each phase. It is most appropriate to have the facilitator discuss his or her own awareness of the impact that emotional factors may play on the nature of the conference. By clarifying these points, all members are aware of the task before them, and at the same time can appreciate the flexibility of the conference's structure in terms of time, their feelings, and the need to obtain closure on the information at hand.²

The conference can then begin by introducing all appropriate information to each member (corresponding again to Level I). There is usually an abundance of information available for discussion. As the clinician carries the role of sharing evaluation results with the parents and child, it is useful to establish priorities for information to be presented. The advantages of establishing priorities are many. The amount of information presented is limited, thereby reducing overload, and the information is presented according to the goals established in Evaluation phase activities. When so much information is to be discussed, the need for relevancy is paramount.

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The positive or negative aspects of the information will also have an impact upon both the presenter and receiver. The clinician has had a chance to review and interpret findings, but the parents and child have not. They are more or less confronted with the information. Therefore, while this part of the conference deals primarily with the presentation of data alone, it must be done carefully and in a way that allows for some degree of integration by parents and child.

By this stage of their involvement with special education, many parents and children are familiar with the terminology and language used. Perhaps they have been through prior evaluations. Nonetheless, the information presented in this first part of the conference is novel in its content and demands sensitive presentation to achieve a measure of integration. For those who have had less exposure to special education, terms such as IQ, retardation, or audio-perceptual deficit may present severe roadblocks to comprehending what is being presented.

Awareness will often occur with the clinician giving information to the parent and child, yet reciprocal exchange of information must exist. Feedback from parents or child is helpful. Confirmation or negation of results can set the stage for more extensive discussion at a later date. It is important, however, to limit the amount of discussion that occurs during the Awareness phase. If too much discussion takes place, critical information may be overshadowed. A reminder of the potential for more in-depth discussion at a later time is appropriate and supports the reciprocal exchange we desire among participants. When all priority information has been presented, it is then time to shift the focus of the conference to a broader discussion of the topics, thus leading into the level of Understanding.

The second portion of the conference (or Level II) focuses on making the awareness information meaningful to all participants. Open discussion now occurs between all members, promoting an opportunity to question, challenge, and digest. Whether initiated by the clinician, parents, or child, there is a need to interpret the basic information. How did the evaluator reach the conclusions? What conclusions do the parents draw? What reaction does the child have? Confidence in the interpretation of test findings is a major issue. It is important to elicit exchange among the members on how they personally accept the data, and how much confidence each has in the various instruments used. It is essential that all needs or feelings related to the information be explored. Every member must actively listen to the other members' feelings and concerns.

Conferences are often carried on in a verbal mode. We are aware, however, that different people learn more efficiently through different modalities. It is wise, then, to employ not only verbal means, but visual and demonstrative methods that will assist the participants in understanding what is being said. Graphs, charts, or percentage tables often are helpful aids. In addition, the participants may wish to model or display experientially a topic that is being discussed. An example would be having a parent copy a design from a mirror: a task to illustrate a child's problems in visual-motor directionality. Information presented verbally may also be written, so that parents can read along with the verbal discussion. In our conferences, we try to provide some written medium that the parents can utilize during and after the conference. The thrust of these various modes of presentation is to ensure understanding among the participants. Finding a way that they can grasp the information most efficiently requires considerable flexibility, but has obvious long-range payoffs. Utilizing analogies that relate more closely to the parents' own experience or philosophical stance is often beneficial.

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Regarding the novelty of the information, there is a need during the Understanding level of the conference to provide definition of terms and explanation of concepts. As stated above, there may be some familiarity with events in the special education experience; still, it is, for all intents and purposes, a completely novel experience for the child and parents. In a short period of time, a great amount of learning needs to occur. There is a chance during this portion of the conference to allude to methods for further learning, such as books or local agencies, that can assist in ongoing development of understanding.

Finally, discussion must occur on what all the information means to each participant. What are the assets and liabilities of the data covered? What are the advantages and disadvantages that may emerge from such findings?

Expectations of each participant in subsequent special education activities need to be explored. What do the parents need to consider in terms of future involvement in their child's education? What kinds of effort will the child need to put forth in order to deal with the newly identified learning disability? What immediate and long-range effects can the parents and child expect? Expectations and language effects fall more directly upon the parents and child because they will be the ones to deal with the learning problem. It is helpful if the clinician offers a supportive role for the short-term education and mobilization of resources to assist in long-range planning. When all the information has been discussed and it is apparent that each participant has a basic understanding of the information, the conference is ready to move to its final stage.

It is now time to develop useful activities for the future (Level III). The decisions reached during

this last portion of the conference may initiate further activities in the Placement phase or a referral to an agency outside the school. In some cases the decision may be reached to take no action at all, which itself is a pragmatic decision.

It is critical to obtain agreement among the participants as to the course of further action. This requires the negotiation process discussed previously. There will often be points of disagreement among the members as to the validity of the information presented, or perhaps to its meaning. Nonetheless, the group must work closely together in order to find areas of agreement on which to base their decisions. A consensus regarding the information must be reached. The process of reaching consensus is enhanced if the participants can explore the available options. The options are, in essence, the goals of future activities. What is available? What are the advantages and disadvantages of various options? While some options may seem appropriate to one member, they may seem inappropriate to another. When discordant views emerge, negotiation is required. Each participant must personally understand the consequences of choosing a particular option, as well as how the choice might affect the other members of the team. The negotiating process allows a clear identification of each participant's role and the expectations of future participation if they choose such a particular goal.

Once the parents, school personnel, and child know the cost and benefits of each decision, they can begin to develop a commitment to embark upon a mutually desirable activity. Again, if we have not reached a consensus, we dilute the possibility of continued useful participation by any one member. We will only delude ourselves into thinking we are making appropriate clinical or academic decisions if we do not have some degree of mutual commitment to

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subsequent activities. Thus, the conference is a starting point to continue working toward some ultimate goal of a child's growth. Agreement upon one small step may mean much more in the long run for the child than the establishment and implementation of activities that lack consensus. The importance of each member in this working team certainly does not end as the conference concludes.

Thus, we have come to the end of the Evaluation phase. Activities proposed to enhance Evaluation phase activities can and should be employed through subsequent steps in the special education process to ensure that maximum involvement by the parent, child, and school can occur.

Summary

The notion of the team has been used throughout this discussion. It is important to emphasize that the working relationship between parents, child, and school requires mutual contribution. It is necessary to have each team member's contributions to ensure the quality and equality of the many activities undertaken during a child's special education experience. If there is too much divergence of energy within this team, we limit the opportunity to enrich each activity along the continuum and run the risk of reducing the maximum potential for the entire process.

A way in which we can accommodate the relationship of the parents, child, and school is to obtain their participation on a consistent basis throughout all activities. The 14 steps identified in the special education experience are a process. The emphasis must be to integrate all members into the process. This integration promotes the recognition that all

team members share the responsibility of making the experience worthwhile. The model we have utilized enhances the feeling of inclusion by providing a medium for exchange of information, active participation, and identification of reinforcing aspects for such involvement.

The reader also may be aware that to elicit useful participation requires that everyone expend time and energy. Time is always an important variable and, in our desire to reach closure, we may often pass over opportunities that will enhance a positive working relationship between the parents, child, and school. It is the author's feeling, however, that all the activities described carry the potential for much larger payoffs. Until such time as we are mandated to share responsibility, activities that promote a shared sense of responsibility need to occur. It is hoped that the reader has gained an appreciation of the complexity of events that make up the special education process, and been given a mechanism, whether it be philosophical or pragmatic to promote the contributions of parents, children, and schools in a way that will make the special education service delivery more productive.

Footnotes

¹There is currently great emphasis upon the use of psychodiagnostic instruments through profile, interpretation, and so on, to identify handicapping conditions. While in the realm of psychometric technology this emphasis is useful, we cannot expect to improve the quality of the evaluation by improving identification through testing alone. There are far too many parameters to a child's display of competence in the testing session that demand broader evaluation of skills and potential contributors to observed deficit areas.

²Exchange of information involving the child is obviously a delicate procedure. Throughout this paper the inclusion of the child in all activities has occurred to emphasize the importance of his or her contribution. The child's active involvement in many of these steps, however, must be undertaken with some modification. Separate interactions are usually advisable. While the procedures remain the same, shorter time frameworks can be employed. In addition, information sharing may be more prioritized in an effort to address the most critical bits of information. In this way, the child does not become overwhelmed. It is worthwhile to assume that the capacity for integration of information is more limited for the child, and as such, we must not confuse him or her with too much involvement. The balance between obtaining the child's useful participation and expecting too much involvement is an area that will need continued explanation.

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Parent Involvement: A Challenge for Teacher Training Institutions

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During the 1960s and 1970s teacher training in the area of special education exploded. The quantity and quality of available information, knowledge, and skills to be included in teacher training curricula grew tremendously. Once it was decided that all children, including the handicapped, had a right to an appropriate education, it was exciting and heartening to observe the responses in institutions of higher education, state departments of education, and local school districts. Because of support from the federal government, both in the area of funding training programs and in the requirements for the education of handicapped children, thousands of well-prepared teachers are in classrooms across the nation. One could probably make the case that the quality of education for exceptional children is presently higher than in any other area of education, from preschool through postsecondary programs.

Most special education teachers know how to formulate and implement an individualized education program (IEP) for children. They know how to write behavioral objectives and how to measure the effectiveness of their intervention. For six hours a day, five days a week, they demonstrate the ability to manage the learning environment and the behavior of the exceptional children in their charge. There is little doubt that they are expert in all aspects of direct child instruction; however, an essential component to the facilitation of child growth is missing in their repertoire of skills. As a result of its absence in their training, teachers often lack expertise in the important area of parent-teacher communication and interaction.

Public Law 94-142 and most state regulations require adult-to-adult involvement, that is, teachers with parents, teachers with other teachers, teachers with administrators, and teachers with other specialists. It has been fairly well accepted that parents, and families in general, have a strong influence on the educational growth and attitudes of children (Coleman, 1966; Jencks, 1972). Why is it, then, that strategies for involving parents have received such low priority in teacher training content? An informal survey conducted by the University of New Mexico Parent Involvement Center a few years ago indicated that only about 20 % of the teacher training institutions across the country offered even one course in parent-teacher interaction. These findings are deplorable in light of the fact that every special educator is required, at a minimum, to communicate with parents about placement and testing procedures, program planning, and educational progress.

Given the fact that teachers, by their own admission, lack the background to work effectively with parents, it has been suggested that other professionals or organizations might help bridge

this gap. For instance, parent organizations such as the Association for Children with Learning Disabilities and the Association for Retarded Citizens might take over such functions as informing parents of their rights and responsibilities and training them to interact with educators and other professionals. As a result, parents could help educate other parents and provide each other with support. While there is no question that parents can do things for other parents that cannot be done by professionals, no matter how sensitive the professionals may be, the reality is that for a great number of reasons, many parents of exceptional children do not come in contact with these parent groups.

In addition to parent organizations, parents have called on advocacy and protection groups for support when they have felt that institutions have been remiss in their practices. For example, an "advocate" may attend IEP conferences or placement meetings either with or instead of the parent. These groups have also been available to educators. If, in some circumstances, educators feel that children are being neglected or not being adequately represented by parents, the court system has allowed various degrees of legal guardianship to be assumed by persons other than the parents. The guardianship responsibilities can range from sitting in on IEP conferences to taking legal custody. Advocacy and protection groups should be supported by both educators and parents, in the best interests of the children in their charge. Many parents, however, will also never come in contact with these groups.

There appears to be a recent realization that the medical profession, too, has some responsibility for being involved with parents. As an example, the January 1982 Journal of Exceptional Children was devoted to "Special Education and Pediatrics: A New Relationship." In a recent workshop with parents of

preschool deaf-blind children (ages 0-6), the parents were asked to grade the performance of the various types of professionals they had seen or were seeing. The top grades were received by teachers and pediatricians. Family doctors received some of the lowest grades. In addition to the range of grades, it was interesting to note the large number of professionals that parents had seen or were seeing. Some parents, in responding to the survey, asked whether to grade the pediatricians they were currently seeing or those they had previously seen, suggesting that they had "shopped around."

While many parents, then, do become involved with medical professionals, that involvement is usually limited and narrow in scope and does not extend over long periods of time. Some exceptional children need limited or no medical management strategies that are related to educational interventions. Educators should support the increased involvement of the medical professions so that there can be some sort of productive alliance of the disciplines. However, although medical professionals may help share the responsibility for communication with parents, the reality is that they probably will have limited impact on the majority of parents.

The one group of professionals with whom parents do have sustained contact over time is classroom teachers. As a result of school policies and good intentions, teachers communicate with parents, for better or for worse. Thus, no matter how successful parent organizations, child advocacy groups, and the medical professionals may be, it is imperative that teachers be equipped to communicate effectively with parents. It is unfortunate that all teachers in training do not have the opportunity to have coursework and experience in the important area of interacting with parents.

Parent Involvement: Teacher Training

The Mirror Model of Parental Involvement

The Parent Involvement Center was originally a federally funded demonstration project in the Albuquerque Public Schools (1978-1981), which was jointly sponsored by the University of New Mexico and the public schools. From our work on this project and subsequent work as a part of the Albuquerque Public Schools, it became clear that there was a need for some type of comprehensive model to put parental needs and strengths, and a variety of subsequent activities into some perspective.

A conceptual framework to guide the development of training content is illustrated by the Mirror Model of Parental Involvement (Figure 1), which has been elaborated on in other publications (Kroth, 1980; Kroth, 1981). The model is an attempt to respect the strengths that parents have, as well as to acknowledge their needs. While the model is comprehensive, it is recognized that probably no one program or one school will contain all of the identified components. In a school system the size of Albuquerque (school population of approximately 80,000 and special education population of approximately 10,000), however, all of the components are found somewhere.

The basic assumptions underlying the Mirror Model of Parental Involvement are that 1) parents of exceptional children are not a homogeneous group; 2) parents of exceptional children have strengths as well as needs to be recognized; 3) educators are not a homogeneous group; and 4) educators also have strengths and needs to be recognized. For the purposes of this discussion, the original Mirror Model has been expanded to differentiate between what the needs and strengths might be and how they might be responded to. The model could just as well

have included another section on who might be responsible for the activities.

The top half of the model addresses the levels of needs that parents may have and how these needs may be met. It assumes that professionals have knowledge and skills that parents need, but it also assumes that not all parents will need or be able to use everything at the same time. The bottom half of the model addresses the levels of strengths that parents may have and how these strengths may be utilized. It assumes that parents have knowledge and skills that professionals or other parents need. It does not assume that all parents will be able to have time to do everything outlined.

Parent Needs

Starting at the midline and working up the model, each level will be discussed briefly regarding the needs of parents. The complementary "how" sections are examples of strategies to meet the needs of parents and/or utilize parental strengths.

Level 1. All parents need some basic information. This strand addresses the knowledge that parents will need in order to exercise their rights and responsibilities. The school system has an obligation to provide parents with this information, and the teacher is in an ideal position to provide this knowledge.

All too often, activities at this level are handled too casually: By the way, you'll need to sign this form before we can test your child, or You may want to look over this handbook that explains our program. Follow-up surveys reveal that parents have not been adequately informed (Thomas, Phelps, & Hopping, 1980). It would seem that some school systems are apprehensive about informing parents

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about their role in consent to test and place, educational programming, and Due Process procedures. This is unfortunate because if school personnel do not do an adequate job, other organizations will, and professionals and parents are then placed in adversary roles.

Making sure that all parents have access to and understand this necessary information is a difficult task. The Federal Register and State Standards are not easy reading. As a result, many school districts have developed handbooks that answer questions that parents have. In addition, some school districts have developed workshops for parents on how to be active participants in the educational programs (Kroth, 1979). The teacher should have a key role in helping parents understand the placement procedure and the contents of a child's folder.

Level 2. Most parents would like information about their child's progress and environment. Information in this strand is also usually provided by the classroom teacher. There are many forms by which this can be transmitted, including handbooks, newsletters, or frequent and regular conferences with parents.

Daily or weekly report card and telephone contact systems are sometimes used for the whole class, or in special cases. Teachers often send home "good news" notes. While the use of daily reporting systems has been well documented in the literature, the establishment of the procedure needs careful planning. Individual consultation or inservice sessions with teachers on how to design and implement such a system can prove fruitful.

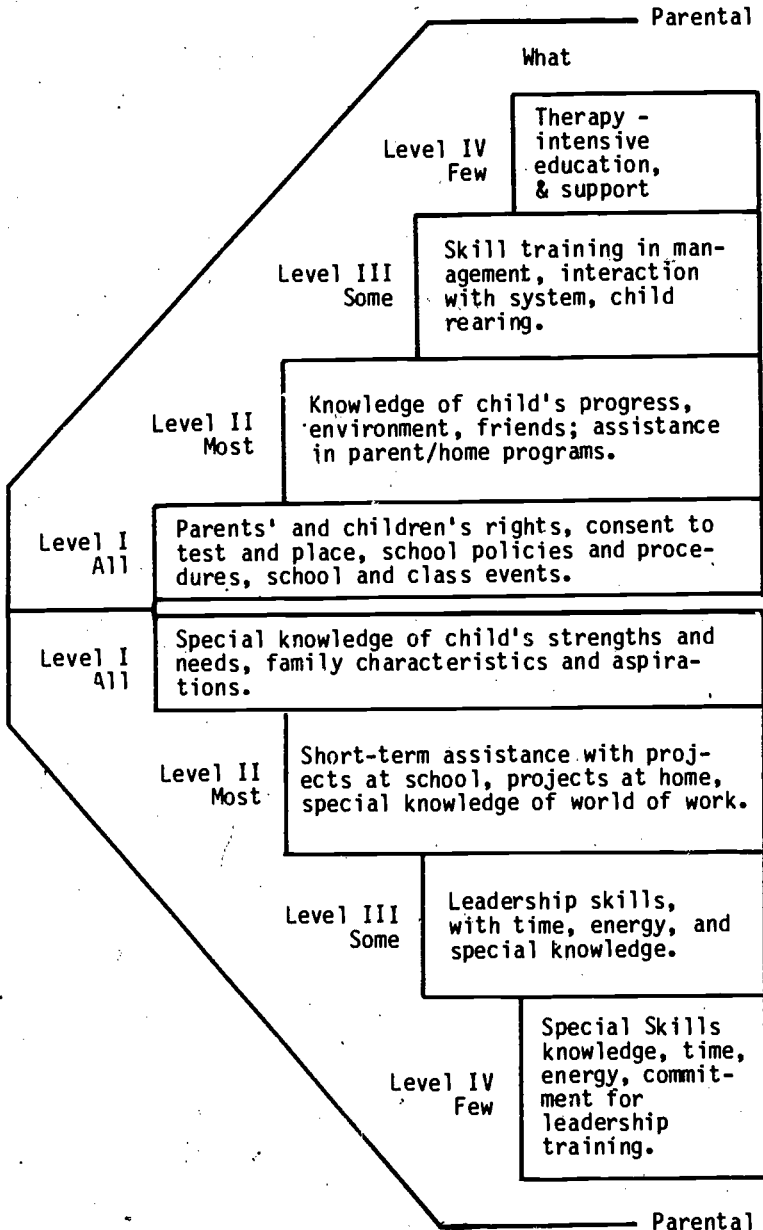
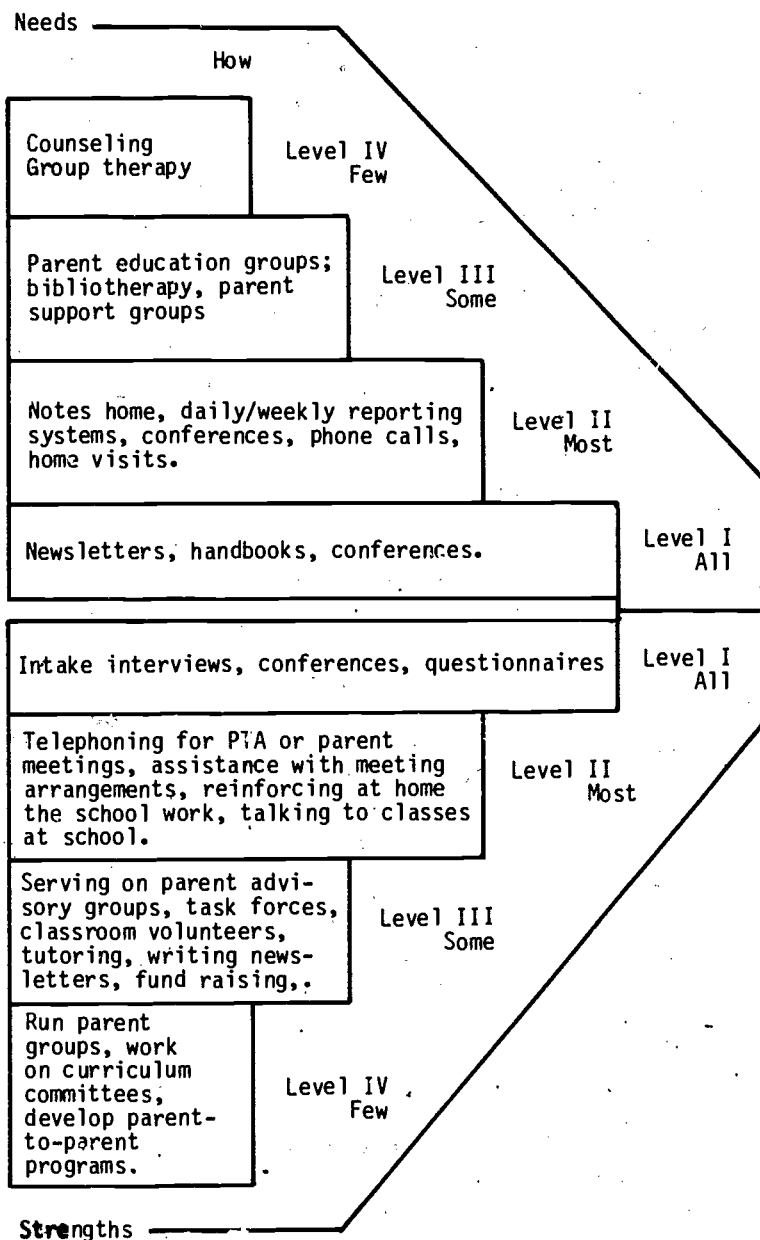


Figure 1. Mirror Model of Parental Involvement

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It should be remembered that many special education teachers have had very little training in holding conferences. Many teacher training programs have not addressed this area and as a result, teachers have been left to carry out this activity with only the knowledge that it is supposed to be done. Inservice sessions should be provided for teachers on this important interaction. Working on listening skills, communication strategies, data interpretation techniques, and conflict resolution skills would be especially helpful for teachers.

Level 3. This strand seems to be the most popular among the professionals, as reflected in the literature, and yet only some of the parents will elect to become involved. It is estimated that only 20 to 40% of the potential parent population will attend skill training parent groups at any given time. The low turnout is probably because of lack of energy, and/or time, family stress, or lack of motivation for the type of activities the professionals have planned for the meetings.

Professionals tend to engage in "tunnel vision" with regard to parent training groups, according to Doernberg (1978). If the professional has a behavioral orientation, then all parents are encouraged to learn behavioral techniques, or if the professional has acquired training in Parent Effectiveness Training (Gordon, 1970), then all parents are offered training in this strategy.

There are probably an infinite number of parent group programs that could be designed to fulfill the expressed or anticipated needs of parents. A teacher skilled in group process can design any number of programs (Kroth & Scholl, 1978). In addition to the more traditional or "canned" programs, other programs have been designed to teach parents to test their own children, to make nutritious snacks, to make puppets to increase

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language, to teach toileting, to teach assertive techniques, to help their child make the transition to elementary school, middle school or high school, to explore vocations, and to write IEPs.

- The staff at the Parent Involvement Center usually attempt to involve the classroom teacher(s) in the design and implementation of parent groups. Quite often the teacher has established a good relationship with the parents and has a good idea of the desired content.

Level 4. Even if the activities described in the first levels are carried out in a systematic way, a few parents will probably need in-depth training or therapy. The teacher is in a good position to refer parents to the appropriate agencies.

It is highly probable that many of the parents' anxieties and feelings of guilt can be alleviated by information, knowledge, and skills provided in Levels 1, 2, and 3. It is also possible that a skilled psychologist will be able to identify parents in these levels who are going to need a different program, such as those who are emotionally drained and whose coping skills are depleted. Individual counseling or the formation of support groups led by trained personnel may be made available. Parent education and counseling is one of the services identified under PL 94-142.

Parent Strengths

Starting at the midline and going down the model in Figure 1 are levels of strengths, or areas in which parents can contribute to a comprehensive parent involvement program. Parents have information, knowledge, and skills that can be useful to professionals and other parents.

Level 1. All parents know things about their children that professionals need to know. This knowledge may include such things as what is reinforcing to the child, or how the child learns best, or a variety of developmental milestones. Much of this information can be obtained in the form of the case history that is usually taken when a child is being considered for a program.

School districts vary as to who is responsible for taking the case history. It may be the school psychologist, a school social worker, a special education coordinator, or a teacher. If this activity is not coordinated, the parent may be placed in the position of repeating the same information many times. It would seem desirable for the people who need family information to get together and develop a form that would include all of their needs. If it could be designed so that multiple copies could be made, each of the significant adults could have a copy.

Level 2. Most of the parents will be willing and able to do some additional tasks on a short-term basis or some that do not take them out of the home. They may be willing to reinforce at home what goes on in the classroom if the teacher is using a daily or weekly reporting system. They may be willing to supervise their child's homework assignments. Most will be willing to serve on telephone calling committees or help with field trips, if these events do not occur too often. Some parents will be willing to talk to students about vocations and the world of work. Others will be willing to tutor in the classroom occasionally.

Coordinating these short-term activities takes time. It involves matching parent strengths with educational and professional needs--usually on a short-term basis. The teacher or special education coordinator, who has an opportunity to view a number

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of programs and parents, is in an ideal position to coordinate these services.

Level 3. Some of the parents will have the time, strength, knowledge, and skill for a more concentrated commitment. When one views parents as a heterogeneous group, it becomes obvious that some will be professionals with leadership training. It behooves educators to tap parents with special skills as resources and utilize their skills in relevant ways.

Advisory groups that include parents can be an important asset to special education programs (Kroth & Scholl, 1978). In most organizations, newly elected officers are offered some leadership training. This often does not happen in public school advisory groups. Parent participants often are not given any training at all in the roles that they assume. As a result, school administrators take on the leadership roles and parents may feel used, rather than being contributors.

Task force groups are another way of using parents to assist in problem solving. For example, parents in the business world can be quite helpful in making curriculum recommendations for students in vocational training programs. It is important, however, that the mission of the task force be clearly defined. Most people, including parents, do not mind contributing time and effort to problem-solving activities if they feel that the products that emerge will be useful and used.

Organizing, planning, and coordinating these activities can be a time-consuming task for the educator, but necessary if the resources within the parent groups are to be utilized. Leadership training for parents requires the teacher to be knowledgeable about the roles people are expected to play, and to have the skills to train parents for

these roles. The acquisition of these skills should be required in teacher training programs.

Level 4. A few parents will have the time, strength, and ability to implement parent-to-parent programs and parent groups. They might even agree to serve as advocates for other parents. However, it is essential that these parents are prepared for the tasks they have agreed to accomplish. Recently, the staff at the Parent Involvement Center have been involved in training parents to be advocates and parent group leaders. The training sequence for becoming a group leader is somewhat lengthy. First, the parent goes through the program as a participant. If, for instance, it is a behavior management program, the parent would demonstrate the ability to take data and modify behavior. Second, the parent would act as an assistant to the group leader. At this stage, the parent would learn to use the audio-visual equipment, offer assistance to parents, and observe the leader. After the sessions, the leader and parent critique the delivery of the workshops. Third, the parent takes the leadership role and is assisted by the parent trainer. Every time the parent goes through the program, it increases the number of cases and examples the parent can draw from in future groups. The parent can then go on to help teachers who would like to implement parent groups in their schools. This sequence seems to be effective.

As one runs groups, one should be on the lookout for potential group leaders. There are many side benefits to using parents in this capacity. They can often relate well to other parents; the "I've been there" attitude can sometimes create rapport quite quickly. Leading groups also increases one's skills in the technique; in other words, one often learns better when one is trying to teach someone else. A third benefit is that the experience often

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increases the self-concept of the parent. One mother, for instance, who was running a behavior management program lost 44 pounds. She said that if she were going to teach parents to manage behavior, she thought she should manage her own.

Comprehensive parental involvement programs are a rarity. All too often only one or two strands of the Mirror Model are attended to in the name of parent involvement. Professionals often point to monthly meetings, or a parent group, or parent conferences as their parent programs. These activities, however, are merely a part of what should be a comprehensive program. A program analysis sheet is useful in planning (Table 1).

The analysis profile is not meant to be all inclusive, but it does pinpoint activities that might be included in a comprehensive program. The assumption is that not all things need to be in place at the same time, but that analyzing one's current programs can lead to decisions about the next logical steps. Using parents in a task force (Level 3 activity) to determine future components could be a viable way to proceed. Whatever strategies are chosen, parent involvement is too important to be left to chance.

Influences on Parental Involvement

As the Mirror Model suggests, there are many factors that influence parents' level of involvement in the education of their children. In society as a whole, well over 50% of school age children have both parents working, and in some areas the percentage is higher--if the parents can find jobs. Over half of our children will live in a single parent family by

Table 1
Parent Involvement Program Analysis Sheet

Often
Sometimes
Seldom
Priority
Projected
Start
Date
Person(s)
Responsible

Kroth, Otteni, & Parks

1. Provides written information on consent to test.
2. Provides written information on consent to place.
3. Provides written information on criteria to place.
4. Provides written information on due process procedures.
5. Provides written information on availability of child's records.
6. Has regularly scheduled conferences.
7. Involves parents in planning the IEP.
8. Has a newsletter.
9. Has parent information group meetings.
10. Uses daily/weekly report cards.
11. Makes home visits.
12. Has class handouts.
13. Makes phone calls systematically.
14. Uses "good news" notes.
15. Interprets test results.
16. Arranges skill training parent workshops.
(Behavior modification, Parent Effectiveness Training, problem solving)
17. Takes family history.
18. Elicits child strengths from parents.
24. Involves parents in Special Interest Task Forces.
(curriculum, discipline, needs & strengths assessment)
25. Uses parents as co-partners for other parents.
26. Uses parents as workshop leaders.
27. Other.

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the age of 15. Only 10-15% of our children at any one time live in the traditional family depicted in our old first-grade readers, where the father goes off to work in the morning, the mother stays home and bakes cookies, there's a boy for you and a girl for me, a dog named Spot, and a cat named Puff. Data on families of exceptional children may be even more dramatic. In an informal survey of 15 middle school teachers of behaviorally disordered children, it was reported that about 40% of the children were living in single parent families at that time. In addition, there were a number of reconstituted families. Most schools do not seem to take these factors into consideration when scheduling opportunities for involvement or interaction.

The Mirror Model has taken into consideration the different levels of involvement that parents can accommodate. This approach is supported by Bell and Harper (1977), who postulate a bidirectional model of parent-child relations. In essence, the bidirectional model asks the practitioner to consider that a child's behavior affects the parent's behavior, as well as the parent's behavior affecting the child. A child who is unattractive, cries, and soils may not receive the warm, caring attention that the child who is happy, attractive, and easily trained does. Children in special education programs often push parents to the limits of their control.

The Mirror Model goes one step further. We would like to suggest a tridirectional model or, if you will, a Parent Trap. When a child is exceptional, professionals often get involved in the intervention between child and parent, either at the invitation of the parents, because it is required (PL 94-142), or because it seems the right thing to do. If the child is multiply handicapped, the number of professionals may be quite large. Even well-researched, proven programs and well-meaning

professionals might be too much for some parents to handle. Doernberg (1978) suggests that the family structures and stresses are seldom analyzed before programs are recommended. A tridirectional model places the parent in the middle, with demands coming from the child on one side and from professionals on the other. In fact, well-meaning professionals often become part of the problem rather than part of the solution and may even contribute to the parents' sense of guilt at not being able to meet all the expectations placed upon them.

The Mirror Model suggests that not all parents will have the strength, knowledge, time, or energy to take advantage of all the "help" that professionals have to offer. Consider the following scenario that occurs frequently in the public schools. Teachers are given release time for conferences and the children are sent home. In special education, there are often children who require a teacher and an aide for educational programming and management. Many of the children have both parents working or, if it is a single parent family, that parent is working. Even when the parent is at home, if the child is severely handicapped or maladjusted, it will probably be difficult to arrange child care for the parents to come to the conference. What are the options for parents? In some cases, it means losing a day's pay, taking the child to a conference, being told to do things the parent does not have the time or strength to carry out, or not showing up for the conference and being labeled a noncaring parent.

Implications for Teacher Training

There are at least four implications for teacher training that can be drawn from the previous discussion. These implications involve teacher

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sensitivity, direction of parent training, communication skills, and acquisition of skills relevant to parent-teacher interaction.

One of the most obvious skills a teacher must display is sensitivity toward the effects of having a handicapped child in the family. In the weekend workshop for families of deaf/blind children that was mentioned earlier, college students were used as child-care workers for twenty-four hours a day while the parents were in meetings. At the end of the sessions, some of the students remarked that when they became teachers they would think twice before they asked parents to take on anything extra. Obviously, this experience provided an excellent opportunity for future teachers to realize the extent to which a handicapped child can affect the family constellation. While it may not be possible to provide every teacher with this type of experience, other opportunities are available to increase their sensitivity. Short of direct child care, having panels of parents speak to teachers about what it is like to have a handicapped child can be worthwhile. It should be remembered, however, that the parents who participate in these panels may not be the ones under the most stress or the most representative. It is difficult to generalize about the reactions to having a handicapped child in the family because of the large number of variables that enter into the picture.

Another approach to increasing teacher sensitivity may be to arrange interviews between teachers and parents of a handicapped child. This is a more complex process than a panel, because the teacher must have sufficient interview skills. In the event that the teacher does not feel comfortable in an interview situation, it may be possible to provide video tapes of interviews with parents of handicapped children. Excellent follow-up activities can be arranged to ensure a beneficial outcome.

A second implication for teacher training drawn from the Mirror Model is that parents may not be as interested in training programs that focus on their being "teachers." Stevens (1982) points out in her review of the literature that most of the parent training programs are centered around teaching parents to accomplish educational goals with their own children, whereas few programs deal with teaching parents how to interact with professionals they encounter. The latter may be a more relevant area to focus on in parent training. Although most parents may not be able or want to be teachers of their children, they do want to be informed. Dembinski and Mauser (1977; 1978) conclude from their research that parents do want information about how their children are doing in school. Thus, the strategies or techniques suggested on the lower or informational level of the Mirror Model, which demand the least in terms of time, energy, or sustained commitment from parents may be the most appropriate. If this is the case, teachers need to be trained to use various communication tools such as daily reporting systems, handbooks, newsletters, and so on.

A third implication for teacher training is the need for teachers to be able to communicate effectively with all types of parents. Looking at Levels 1 and 2 of the Mirror Model, where most of the activity will reach most of the parents, it is obvious that the teacher will bear a large part of the responsibility for communicating a wealth of information. In addition to providing information about a child's progress, the teacher will be offering information about various services within the community that may benefit the child. Both types of information are often offered in written form. Face-to-face communication involves another set of skills. Briefly, teachers will need to be able to build trust and rapport, paraphrase and make perception checks, build upon parental suggestions,

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and generally facilitate the receiving and sending of verbal and nonverbal information. The effectiveness of the communication process is often a function of the attitudes, knowledge of subject matter, sociocultural background, and communication skills of both the source and the receiver. Communication breakdowns are inevitable; however, they can be minimized if conscious efforts are made to avoid pitfalls and to learn from one's mistakes.

Finally, teacher training programs should emphasize the acquisition of skills necessary at Levels 1 and 2 of the Mirror Model. Teachers should be successful at Level 1 and 2 activities before attempting to establish programs connected with Levels 3 and 4. This is a pragmatic decision based upon the reality that most teachers will not run parent education groups and most parents could not or would not attend them if they were offered.

Teacher Skills

During the 1978-81 project period, the authors developed a workshop and materials called "Strategies for Effective Parent-Teacher Interaction" designed for teacher trainers. Professors from six universities who were engaged in training teachers to work with parents were consultants on the project. Week-long training institutes were delivered and are still being conducted for participants from across the country.

The content was designed around the functions that most teachers are expected to perform when interacting with parents. By drawing upon available research results regarding legal responsibilities and past experience, the topics selected were:

1. Values Clarification. Often teachers individualize for children but not for parents. In order to individualize, the teacher must have

a basic set of information about the parents and family structure, including an understanding of the values upon which the family operates. None of us has exactly the same set of values as any other individual. Neither are we aware of our own deeply held values until we are confronted with them. Parent-teacher conferences are frequently an avenue whereby values can be explored and understood to avoid potential conflicts. A recognition that parents have a variety of value systems, economic backgrounds, educational levels, and social expectations can facilitate communication between school and home.

2. **Family Dynamics.** Most teachers need to expand their knowledge about what it is like to have a handicapped child in the home. There is considerable literature describing family dynamics when a handicapped child arrives on the scene, but actual face-to-face experiences should not be overlooked. The use of video documentaries and/or interviews is helpful, especially if followed by in-depth discussions. Interviewing parents on a one-to-one basis and having parent panels are other useful strategies. Sharing a camp experience can also provide valuable insights into the complex feelings and responsibilities connected with having a handicapped child for 24 hours a day.
3. **Communication Techniques.** Because parents cannot always attend conferences or visit school, other techniques for keeping the parent informed are pursued. Two types of information should be continually offered to the parents: 1) pupil progress information and 2) the availability of additional services within the community that may benefit the child and/or family. Pupil progress information can be transmitted by the use of daily reporting systems such as informal notes, notebook

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exchanges, scrapbooks, telephone calls, and home visit techniques. It may very well be that with microcomputer printout technology, telephone conferences may take on increased importance. Most parents would like additional information, such as activities to do at home with their children, appropriate gifts, available summer programs, community services and field trips. School handbooks and monthly newsletters are excellent ways to offer this information to parents.

4. Conferencing Skills. Because all teachers hold conferences, a fair amount of time is devoted to this area. Parents of handicapped children are faced with many complex and diverse problems associated with their child's condition. There are certain conferencing skills that increase the probability of a positive relationship between parent(s) and teacher. Teachers are taught how to arrange the conference environment, how to open and close a conference, how to deal with aggression, how to establish rapport, acceptance, respect, trust, and perhaps most importantly, how to listen to the parent's messages and provide clear messages to the parents(s).
5. Legal Information. The issue of informed consent seems to be cloudy for most educators. Program changes are made without informing parents. IEPs are written prior to conferences and parents are merely asked to sign. Due process procedures are not explained to parents. Parents often do not know what the categorical classifications of their children are, what types of programs they are in, or what kind of services they are entitled to have. Teachers must become familiar with their legal responsibilities, and, in turn, impart the necessary information to parents.

6. Other Content Areas. There are, of course, many other content areas and skills that may be stressed in teacher training programs. For example, almost every teacher at some time or other has to impart "bad news" to another person. Often, this is done poorly, because the teacher does not realize the distortions and blockages the parent may be experiencing. These types of communication gaps need to be explored and training should be provided to bridge them.

Strategies for effectively utilizing the strengths of parents should be included in teacher preparation programs. Parents can be used as aides, tutors, newsletter designers and writers, advisory board members, field trip aides, parent teachers and more, but they need training, too. So, in essence, teachers must also be trained to work with parents who will assume these new roles. Teacher education must go beyond teaching the child. Adult education techniques and strategies now must become a vital part of teacher education.

Although parent groups can be an effective means for teaching parents specific skills to use with their children and with professionals, it is the authors' opinion that university staffs have placed too much emphasis upon this type of parent training. Other forms of parent communication need to be stressed at teacher training institutions. The parent program must be geared to the needs and energy levels of parents. This is particularly true for parents with children at the school age level. Parents get burned out, overworked, tired, and dissatisfied with programs that do not fit their needs.

Conclusion

It should be obvious that the authors take the position that strategies for effective parent-teacher interaction should be integral parts of any teacher training program. The primary responsibility for interacting with parents cannot be abrogated or assigned to parent coalitions, child advocacy groups, or medical and allied professions. No other group of people has the frequent and sustained contact with parents that teachers do, nor is any other group so vested with the trust and hope for the success of their children. There are identifiable competencies to be taught to teachers and techniques for improving the relationship between home and school. The interactions are mandated by law and school policy and are educationally sound and experientially satisfying. Why universities and colleges have not addressed this important area of teacher education remains a mystery. It is past time to focus our energies on remedying this oversight.

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